



Comprehensive Review and Analysis

2025 Missouri Statewide Needs Assessment

Prepared for:



By:

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August 1, 2025

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Table of Contents

Table of Tables	iv
Table of Figures	vi
Acknowledgements.....	vii
INTRODUCTION.....	1
STATE DISABILITY CHARACTERISTICS.....	2
PREVELANCE OF DD IN STATE AND EXPLANATION OF PREVALENCE	2
RACIAL AND ETHNIC DIVERSITY OF THE STATE POPULATION	3
LANGUAGE SPOKEN AT HOME	4
RESIDENTIAL SETTINGS	5
Key Points.....	6
DEMOGRAPHICS OF ADULT POPULATION WITH DISABILITIES.....	6
Age and Disability Type	6
Sex.....	7
Hispanic/Latino Ethnicity.....	8
Race	8
Key Points.....	9
MISSOURI COMPREHENSIVE REVIEW AND ANALYSIS	10
RESULTS	10
ANALYSIS.....	11
Statistical Tests.....	11
Qualitative Data	12
ABOUT YOU	12
WHAT YOU DO	16
Individuals with IDD vs. Family Members—Daily Activities	17
Age Group Differences—Daily Activities.....	18
Disability Groups—Statistical Significance of Daily Activities	19
Case Management / Support Coordination—Daily Activities	19
Challenges to Getting a Job.....	19

Key Points	21
LIFE TRANSITIONS	22
Individuals with IDD vs. Family Members—Life Transitions	23
Age Group Differences—Life Transitions	24
Case Management / Support Coordination—Life Transitions	24
Challenges to Transition Support	25
Key Points	26
WHERE YOU LIVE	26
Challenges to Obtaining Needed Living Options	27
Individuals with IDD vs. Family Members—Living Arrangements	28
Age Group Differences—Living Arrangement	29
Case Management/Support Coordination Differences—Living Arrangements	30
Key Points	30
FUTURE NEEDS	31
Individuals with IDD vs. Family Members—Statistical Significance	33
Differences Between Age Group—Statistical Significance of Future Needs	34
Differences among Disability Groups—Statistical Significance of Future Needs	35
Case Management & Support Coordination—Statistical Significance of Future Needs	35
Key Points	35
FAMILY NEEDS	36
Challenges to Obtaining Supports and Services that the Family Need	37
Age Group Differences—Statistical Significance of Family Needs	38
Case Management / Support Coordination Differences—Statistical Significance of Family Needs	38
Key Points	38
Appendix A	39
Chi-Square Analysis of Daily Activities	39
Appendix B	44
Chi-Square Analysis of Life Transitions	44

Appendix C	48
Chi-Square Analysis of Living Arrangements	48
Appendix D	51
Chi-Square Analysis of Future Needs	51
Appendix E	58
Chi-Square Analysis of Family Needs	58

Table of Tables

Table 1. Estimated Prevalence of Developmental Disabilities in Missouri.....	2
Table 2. Language Spoken at Home in Missouri, 2023.....	4
Table 3. Disability Status and Types among Adults 18 Years of Age or Older by Sex in Missouri, 2022	7
Table 4. Listening Session Profiles	10
Table 5. Participant Demographics.....	12
Table 6. Living Arrangement.....	14
Table 7. Primary Daytime Activity	15
Table 8. Daily Life Activities—Individuals with IDD vs. Family Members.....	18
Table 9. Challenges to Getting a Job	20
Table 10. Transitions—Individuals with IDD vs. Family Members	23
Table 11. Challenges to Transition Support	25
Table 12. Challenges to Obtaining the Living Options that you Need	28
Table 13. Living Arrangement—Individuals with IDD vs. Family Members	29
Table 14. Future Needs—Individuals with IDD vs. Family Members.....	33
Table 15. Challenges to Getting the Supports and Services that You and Your Family Need	38
Table 16. Chi Square analysis of Daily Activities by Age Group.....	41
Table 17. Chi Square analysis of Daily Activities by Disability Type	43
Table 18. Chi Square analysis of Daily Activities by Case Management / Service Coordination	44
Table 19. Chi Square Analysis of Life Transitions by Age Group	46
Table 20. Chi Square analysis of Life Transitions by Case Management / Service Coordination	48
Table 21. Chi Square analysis of Living Arrangements by Age Group	50

Table 22. Chi Square analysis of Living Arrangement by Case Management / Service Coordination	51
Table 23. Chi Square analysis of Future Needs by Age Group	53
Table 24. Chi Square Analysis of Future Needs by Disability Type	57
Table 25. Chi Square analysis of Living Arrangement by Case Management / Service Coordination	58
Table 26. Chi Square analysis of Family Needs by Age Group	60
Table 27. Chi Square analysis of Family Needs by Case Management / Support Coordination	61

Table of Figures

Figure 1. Heat Map of Responses to the CRA Statewide Survey	2
Figure 2. Percent of Population by Race, 2023.....	3
Figure 3. Languages with more than 10,000 speakers in Missouri (other than English).....	4
Figure 4. Long-Term Supports and Services Recipients by Residence Type (2023).....	5
Figure 5. Disability Status and Types among Missouri Adults, 2022.....	7
Figure 6. Disability Status and Types among Adults 18 years of Age or older by Race/Ethnicity in Missouri, 2022	8
Figure 7. Case Management/Support Coordination.....	14
Figure 8. Who Completed the Survey?.....	15
Figure 9. Most Important Daily Activities.....	16
Figure 10. Most Important Unmet Needs	17
Figure 11. Most Important Life Transitions Needs	22
Figure 12. Most Important Unmet Life Transitions Needs	22
Figure 13. Most Important Living Arrangements	26
Figure 14. Most Important Unmet Living Needs.....	26
Figure 15. Most Important Future Needs	31
Figure 16. Most Important Needs for Additional Information in Next 5 Years	32
Figure 17. Most Important Family Needs	37
Figure 18. Most Important Unmet Family Needs	38

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- Missouri APSE
- Missouri Family to Family
- People First of Missouri
- People First of Monroe
- People First of Pettis County

INTRODUCTION

The Missouri Developmental Disabilities Council (MODDC) began planning for the 2022-2027 five-year state plan in late 2019. The MODDC partnered with the University of Missouri-Kansas City's Institute for Human Development (UMKC-IHD) to develop the Comprehensive Review and Analysis (CRA) of needed systems-change and capacity-building related to services and supports for people with intellectual and developmental disabilities (IDD) in Missouri. In the early planning period, the MODDC worked with UMKC-IHD to establish a timeline and process to develop the CRA.

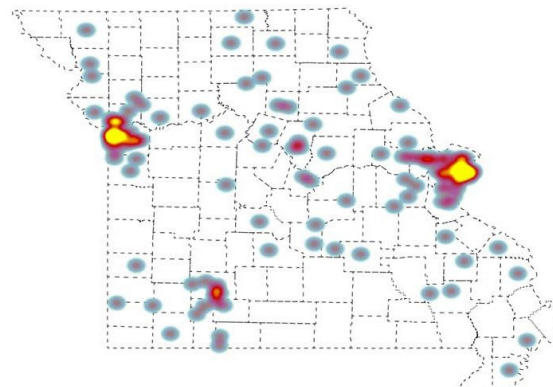
Throughout the process, the MODDC and UMKC-IHD worked with a statewide network of partners to gather data to inform actionable, community-driven policy and program recommendations. In the autumn of 2024, UMKC-IHD began compiling the CRA, gathering relevant existing data and developing a strategy to collect qualitative and quantitative data from a diverse range of Missourians with IDD and stakeholders. Leadership and staff at the MODDC and UMKC-IHD met several times to create a plan and were in regular communication regarding relevant data sources.

As in previous years, a needs assessment survey was developed to gather data from people with IDD and their families. This Institute for Human Development at UMKC developed the survey and the MODDC reviewed it and suggested adding questions largely related to food security and emergency preparedness. The Institute for Human Development at UMKC made these additions and finalized the survey. The UMKC-IHD project team had the survey translated into Spanish and reviewed by two Spanish-speaking staff members. The team published online the English and Spanish versions of the survey and made paper copies available for in-person data collection. The responding period for the survey ran from early February 2025 through the end of May 2025.

Various community partners across the state assisted with dissemination by promoting the survey on organizational listservs, websites, social media posts, and more. Many organizations sent multiple emails or included information about the survey in multiple newsletters. The Institute for Human Development at UMKC publicized the survey through social media and email blasts and promoted it during 13 listening sessions held between February and May. The MODDC shared information about the survey through its website and social media channels. Partner agencies that assisted with dissemination include: MODDC, People First of Missouri, Missouri Family to Family, local county disability services (SB-40) boards, and the Association on Aging with Developmental Disabilities. Within UMKC-IHD, the Alianzas program provided outreach to Missouri's Latinx community. Alianzas staff members promoted the survey to program members and affiliated organizations via online and phone outreach.

Completed surveys totaled 258 statewide with 242 in English and 16 in Spanish. Figure 1 displays the communities where people who completed the survey lived. In addition to the needs assessment survey, community listening sessions gathered qualitative data and heard directly from Missourians. Between February and May 2025, UMKC-IHD and MODDC staff members hosted 15 listening sessions: 10 in-person regional sessions and five online sessions using Zoom. A minimum of two CRA team members facilitated the listening sessions. Whenever possible, one of the interviewers was a person with an IDD. In total, the project team spoke with 179 participants comprised of 89 individuals with IDD, 20 family members, and 70 service providers.

Figure 1. Heat Map of Responses to the CRA Statewide Survey



STATE DISABILITY CHARACTERISTICS

The following section details information about Missouri's overall population and IDD population, including information related to prevalence and demographics.

PREVELANCE OF DD IN STATE AND EXPLANATION OF PREVALENCE

Accurately estimating the prevalence of disability in a population is challenging, and there are multiple accepted measures of prevalence. Several studies have researched the prevalence of developmental

disabilities, though Larson et al.'s (2001) estimate of 1.58% prevalence rate in a population is one of the most widely accepted. Additional studies shared by the Office of Developmental Disabilities calculate the prevalence rate to be as low as

.76% and as high as 1.7%. Based on these estimations and Missouri's 2025 population of roughly 6.215 million, there are likely between 47,235 (.76%) and 105,657 (1.7%) Missourians with a developmental disability (Table 1). Based on the accepted prevalence of 1.58%, there are approximately 98,199 individuals in Missouri with a developmental disability.

Table 1. Estimated Prevalence of Developmental Disabilities in Missouri

Prevalence Rate	Number of People
.76% (Steinmetz, 2006)	47,235
1.58% (Larson et al. 2001)	98,199
1.7% (CDC, 1996)	105,657

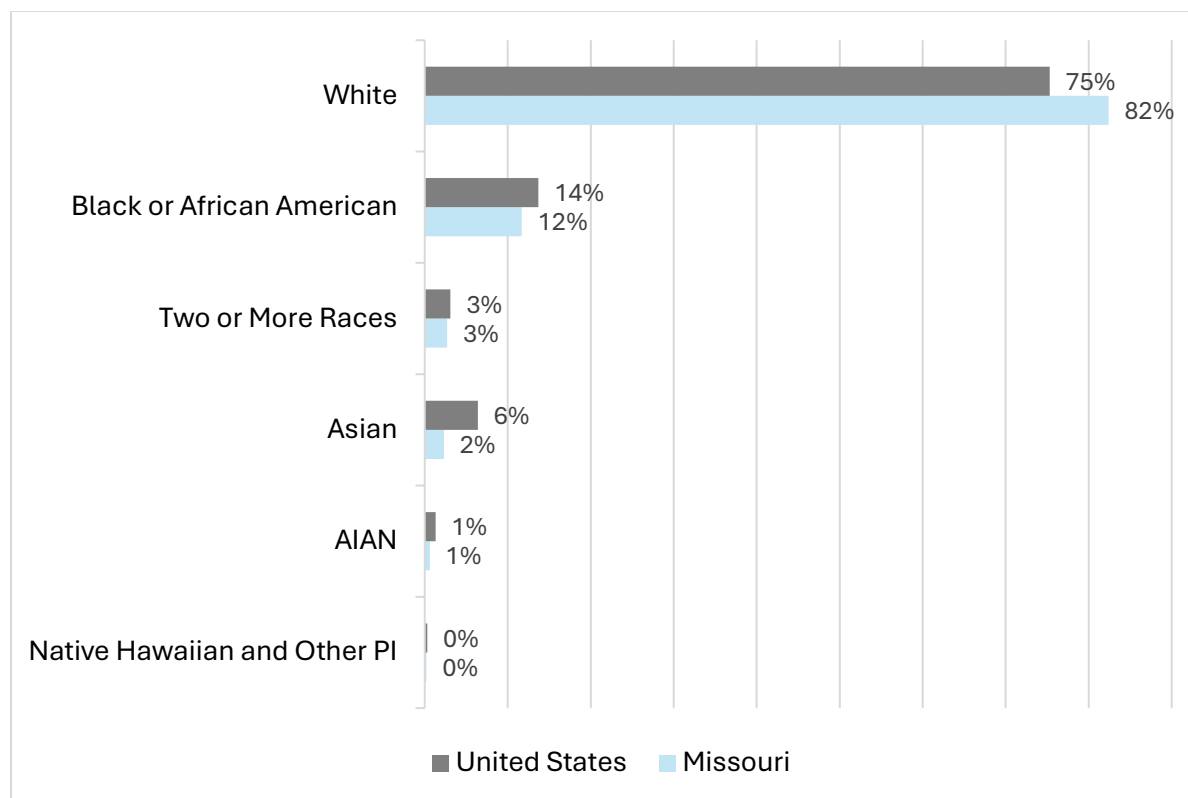
Data for this CRA comes from a variety of sources. Available sources often differ by sample population and definition of disability. Because of this, data must be understood and

interpreted in context. For example, much of the demographic information in this report comes from the U.S. Census, which collects data on physical and cognitive disabilities through the American Community Survey (ACS). While the ACS gathers data on cognitive disabilities, the operational definition of cognitive disability used (“because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions”) does not directly align with other accepted definitions of IDD; however, because the ACS has a large, nationwide sample of disability and other data, it remains a valuable resource and is the recommended source by the Information and Technical Assistance Center (ITACC). According to the 2023 ACS 1-Year Estimates, approximately 15% of the population, or 914,021 Missourians, have a disability of some kind, and 6.5% or 374,200 have a cognitive disability. Nationwide, 13.5% of the population have a disability of some kind and 5.8% have a cognitive disability.

RACIAL AND ETHNIC DIVERSITY OF THE STATE POPULATION

According to the 2023 ACS, Missouri’s population of more than 6.2 million people is roughly 82.4% white, 11.7% Black or African-American, 2.7% two or more races, 2.3% Asian, and less than 1% American Indian or Alaska Native and Native Hawaiian or other Pacific Islander (Figure 2).

Figure 2. Percent of Population by Race, 2023

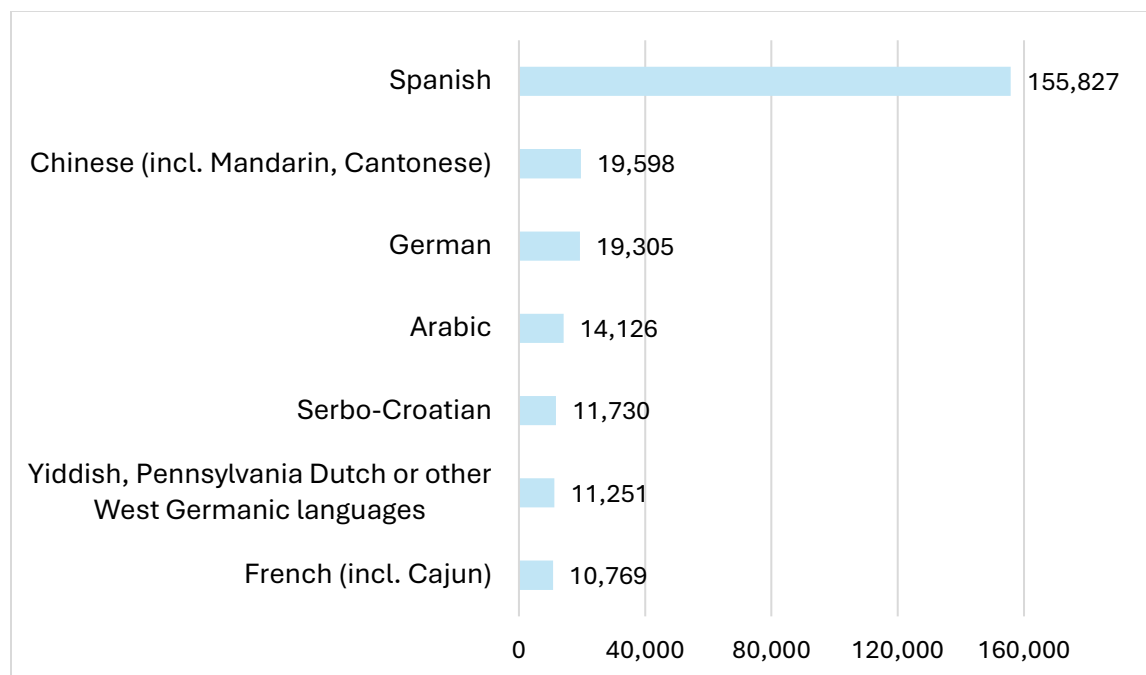


LANGUAGE SPOKEN AT HOME

In Missouri in 2023, 93% of people spoke English at home, while 7% of the population spoke another language at home. Among the 7% who speak another language at home, 97.6% reported speaking English “very well” or better, indicating a high level of comfort with English by most Missourians. Besides English, the most common language spoken at home was Spanish (2.9% of Missouri’s population—and 42% of those speaking another language at home—spoke Spanish, Table 2). Although English is widely spoken in Missouri, numerous other languages are also represented in the state’s population and targeted outreach in other languages—particularly Spanish—can help decrease language barriers experienced by individuals and families. Table 2 and Figure 3 provide more detailed information about the languages spoken at home by Missourians.

Table 2. Language Spoken at Home in Missouri, 2023		
Language	Number	% of Population
Total Households Speaking a Language other than English	407,512	7.0%
Spanish	172,159	2.9%
Other Indo-European Languages	114,762	2.0%
Asian and Pacific Island Languages	79,721	1.4%
Other Languages	40,870	0.7%

Figure 3. Languages with More Than 10,000 Speakers in Missouri (other than English)



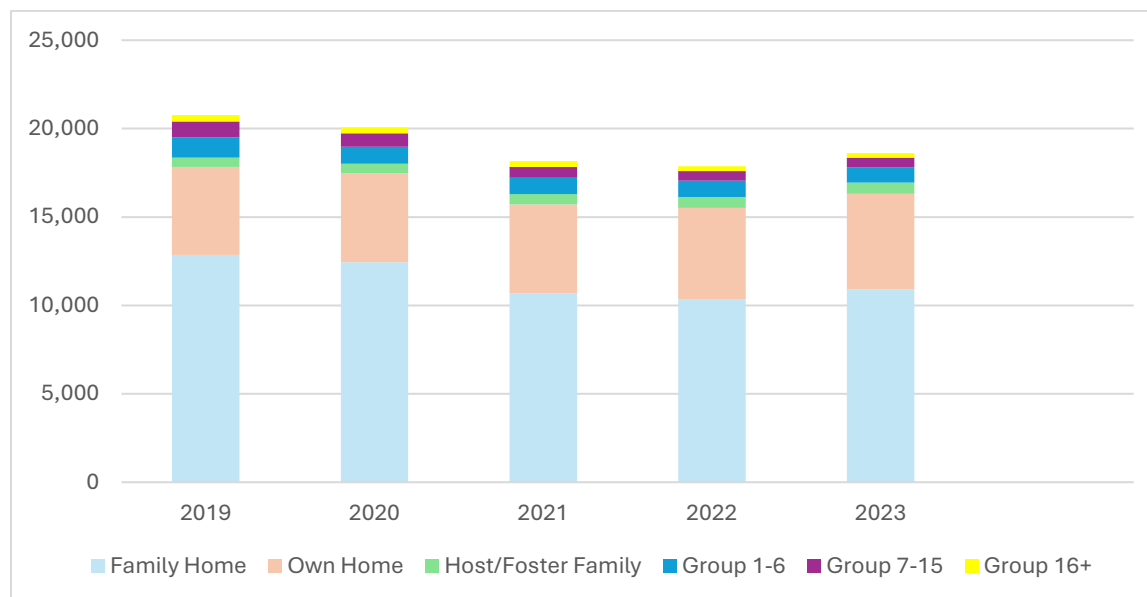
Source: U.S. Census Bureau, American Community Survey, 5-Year Estimates (2018-2022)

RESIDENTIAL SETTINGS

There are currently eight state operated habilitation centers in Missouri: Bellefontaine Habilitation Center (St. Louis), Higginsville Habilitation Center (Higginsville), Northwest Community Services (Marshall), South County Habilitations Center (St. Louis), Southeast Residential Services (Poplar Bluff), Southeast Residential Services (Sikeston), Southwest Community Services (Nevada), and St. Louis Developmental Disabilities Treatment Center. While there are individuals who reside in habilitation centers and receive services through the Missouri Home and Community Based Services (HCBS) Waiver Program, individuals are no longer admitted to habilitation centers for long-term residential services. Current habilitation admissions are exclusively for short-term crisis stabilization. Some habilitation center residents have Missouri's HCBS Waiver Program and receive service coordination and monitoring, like waiver recipients living in other settings.

Figure 4 presents data from the Residential Information Systems Project (RISP), which gathers, maintains, and analyzes longitudinal data on Medicaid-funded, long-term supports and services (LTSS) for people with IDD (<https://risp.umn.edu/about/overview>). It demonstrates that, between 2019 and 2023, the majority of people with IDD (87%) who participated in the Missouri HCBS Waiver Program lived with family or in their own home. The number of people who lived in their own home over that period increased eight percent from 4,982 to 5,422. In contrast, the number of people with IDD who lived in state-run, large group settings (16+ people) decreased 27% during this same period, from 363 in 2019 to 265 in 2023. Additionally, people living in state-run, group settings with one to 15 people decreased by 28% from 1,945 residents in 2019 to 1,397 residents in 2023.

Figure 4. Long-Term Supports and Services Recipients by Residence Type (2023)



Source: RISP State Profiles FY 2023 (<https://publications.ici.umn.edu/risp/state-profiles/missouri>)

Among people who receive LTSS, there are adults with IDD who live in what the Missouri Department of Mental Health calls “inappropriate placements” (Keller, 2023). These

include nursing homes, hospitals, jails, and homeless shelters. In 2023, 650 adults with IDD lived in settings such as these primarily due to a shortage of direct-support employees within local agencies that serve adults with IDD.

Key Points

- There is no single agreed upon estimate of the number of people with IDD, but based on the accepted prevalence of 1.58%, there are approximately 98,199 individuals in Missouri with an IDD.
- Missouri's population is mostly White (82%) and English speaking (93%). Nearly 12 percent of Missourians identify as Black or African American.
- Among the households speaking a language other than English in the home (7%), Spanish (2.9%) is the most common.
- Most people with IDD who receive LTSS live with their families or in their own home.
- The population of Missourians with IDD living in group residential settings declined each year from 2019 to 2023. This continues a trend that began in 2007 (Barton, et al. 2021).
- A small number of Missourians with IDD live in inappropriate settings, including nursing homes, hospitals, jails, and homeless shelters.

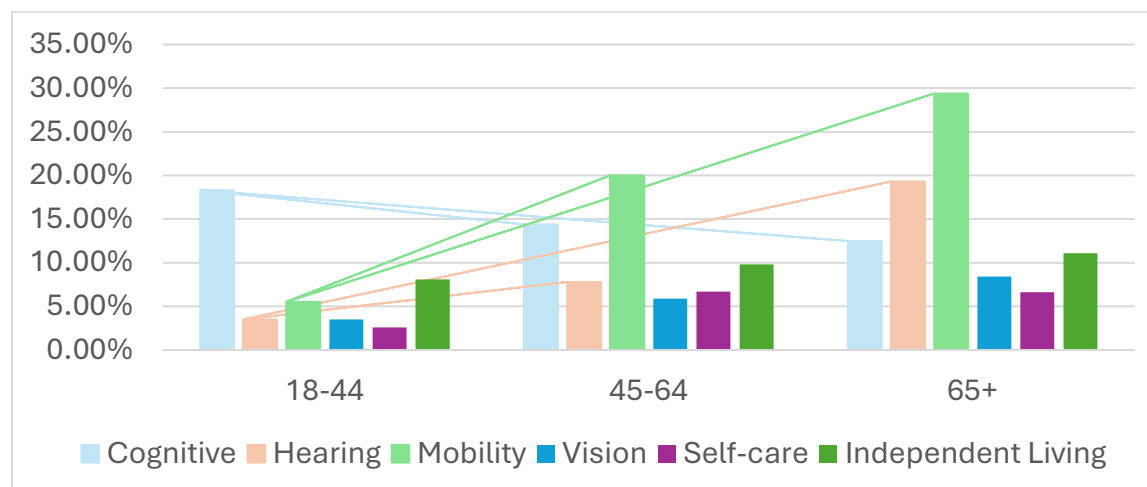
DEMOGRAPHICS OF ADULT POPULATION WITH DISABILITIES

Age and Disability Type

The percentage of people with any type of disabilities increases as the population ages. For example, in 2022, 48.3% of people who are 65 years of age and older in Missouri had a disability. This decreased to 32.5% among people between the ages of 45 and 64 years. Among those between the ages of 18 and 44 years, slightly more than a quarter of the people—25.2%—had a disability (CDC, 2025).

Within each of these age groups, the disability status shifts as the population ages. For example, in 2022, the most prevalent disability for people between the ages of 18 and 44 was cognitive disability (376,284, 18.3%). Among adults who were 65+ years of age, the most prevalent disabilities were mobility disabilities (335,265, 29.4%). Figure 5 below demonstrates the disability status and types among adults 18 years of age or older by age group. While independent living disabilities are not the most prevalent at any age, the data demonstrate that they increase progressively as a person ages. This is also true for hearing and vision disabilities. Interestingly, cognitive disabilities decrease in prevalence as a population ages.

Figure 5. Disability Status and Types among Missouri Adults, 2022



Source: CDC, Disability and Health Data Systems

(<https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>)

Sex

According to the Centers for Disease Control and Prevention (CDC), in 2022, females were more likely to experience a disability of any kind than males. For example, Table 3 demonstrates that females with cognitive disabilities outnumbered males with the same disability by 113,059. There were also more women who experienced mobility, vision, self-care, and independent living disabilities than men. In total, 33.3% of adult females in Missouri had a disability whereas 29.4% of males had a disability of any type.

Table 3. Disability Status and Types among Adults 18 Years of Age or Older by Sex in Missouri, 2022				
Disability Type	Male		Female	
	#	%	#	%
Cognitive	308,346	14.0	421,405	18.2
Hearing	233,932	9.1	175,453	6.1
Mobility	307,716	12.2	435,742	15.5
Vision	116,556	4.8	140,708	5.4
Self-Care	99,810	4.1	129,152	5.0
Independent Living	153,092	6.6	283,860	11.5
No Disability	1,554,754	70.6	1,558,012	66.7
TOTAL	2,251,843	100.0	2,404,851	100.0

Source: CDC, Disability and Health Data Systems

(<https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>)

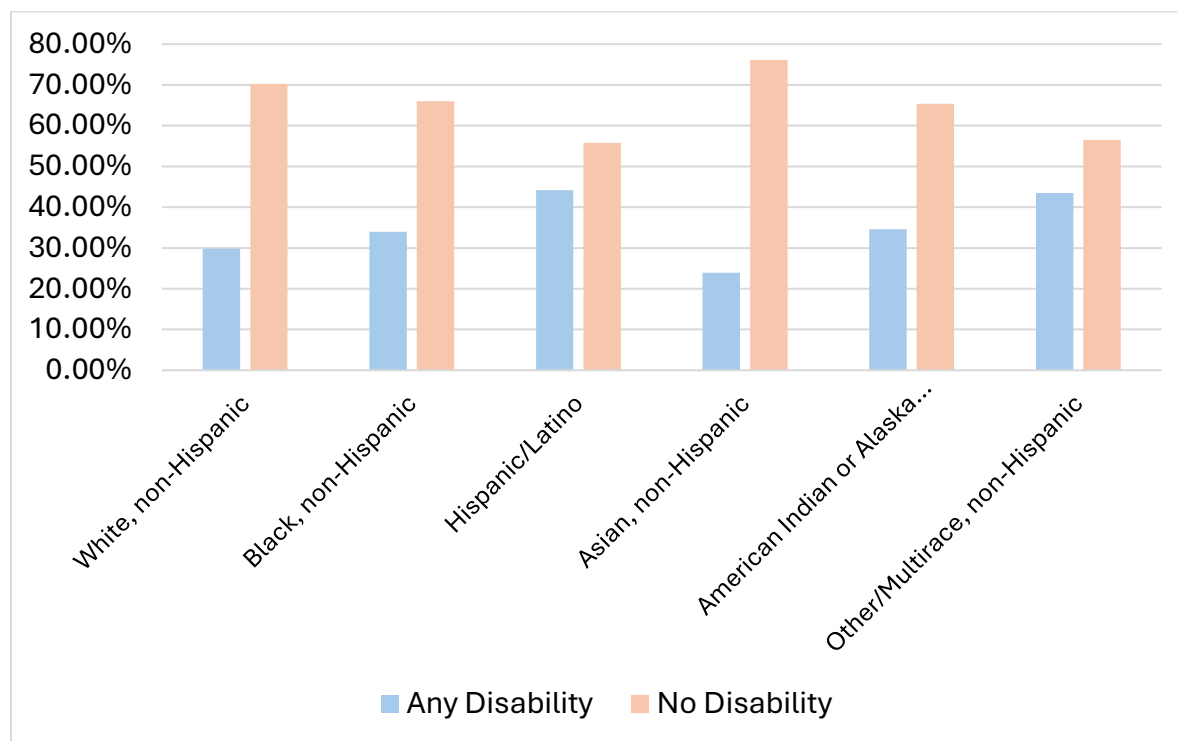
Hispanic/Latino Ethnicity

According to the Census Bureau ACS 5-year Estimate, 5.06 percent of the people within Missouri identify as Hispanic/Latino (312,000 people). Additionally, the most common birthplace for the foreign-born residents of Missouri was Mexico. Among Hispanic/Latino Missourians 18 years of age or older, 44.2% had a disability of any type (see Figure 5 below). This is one of the highest percentages among all race/ethnic groups in Missouri.

Race

In terms of disability status and race in Missouri, a higher percentage of multiracial, non-Hispanic adults 18 years of age and older have a disability than do any other racial groups. Asian, non-Hispanic adults have the lowest percentage of disability (23.9%) followed by White, non-Hispanic adults (29.8%), and Black/African American non-Hispanic adults (34.0%). American Indian or Alaska Native, non-Hispanic adults have a disability status of 34.6 percent. In terms of pure numbers of people with a disability by racial status, slightly more than one million (1,137,860) White, non-Hispanic people have a disability. All other racial groups combined only include 283,200 adults with a disability of any type.

Figure 6. Disability Status and Types among Adults 18 years of Age or Older by Race/Ethnicity in Missouri, 2022



Source: CDC, Disability and Health Data Systems

(<https://www.cdc.gov/ncbddd/disabilityandhealth/dhds/index.html>)

Key Points

- Females in Missouri experience disabilities at much higher rates than males.
- Hispanic/Latino adults in Missouri experience disability of any kind at a very high rate (44.2%).
- Multiracial, non-Hispanic adults in Missouri experience disability of any kind at a high rate (43.5%).
- Cognitive disabilities are the most prevalent disabilities among adults 18 years of age or older; however, the percentage of adults who have a cognitive disability decreases as the population ages.
- As people in Missouri age, mobility disabilities become increasingly more prevalent with nearly 30% of people over the age of 65 experiencing a mobility disability.

MISSOURI COMPREHENSIVE REVIEW AND ANALYSIS

RESULTS

People with IDD and their family members who participated in the CRA provided information by completing a needs assessment survey and/or attending a listening session. The survey was divided into five sections: 1) About you; 2) What you do; 3) Where you live; 4) Future needs; and 5) Family needs. In sections two through five, participants identified the importance of lifestyle issues using the following scale: 1) Not important: I **do not** want or need; 2) Important: my needs **are** met; and 3) Important: my needs **are not** met. Further, at the end of each section, they identified the challenges to obtaining what they needed.

In addition to people with IDD and their family members, the listening sessions included direct support providers and other professionals who work within the field of IDD. As described in the introduction, 179 people participated in these sessions: 89 individuals with IDD, 20 family members, and 70 professionals who provide services. The listening sessions were conversational and revolved around one basic question: “What are the greatest needs facing people with intellectual and developmental disabilities and their families?” Each session tended to have a focus area that affected the conversation. Table 4 below provides a profile of each listening session.

Table 4. Listening Session Profiles			
Date	Location	Host Organization	Participant Profile
3/1/25	St. Charles / Online	People First of Missouri/FACT	32 PWD ¹
3/7/25	Kansas City	UMKC-IHD	3 PWD 4 Family 5 Prof.
3/12/25	Richmond	Ideal Industries	14 PWD 1 Prof.
3/13/25	Columbia	Boone County People First	8 PWD
3/13/25	Online	Missouri Family to Family	7 Family
3/14/25	Online	MODDC/Ideal Industries	3 Family 8 Prof.
3/21/25	Monroe City	People First of Monroe/LOQW	7 PWD
3/26/25	Jefferson City / Online	MACDDS	10 Prof. ²
3/27/25	Springfield	Abilities First	4 PWD 2 Prof.
3/27/25	Online	Missouri Family to Family	6 Family
4/14/25	Kirkville	Adair County SB40	5 PWD
4/17/25	Sedalia	People First of Pettis County	9 PWD
4/21/25	Union	Franklin County People First	7 PWD

Table 4. Listening Session Profiles			
Date	Location	Host Organization	Participant Profile
4/25/25	Online	APSE	14 Prof.
4/30/25	Online	MODDC	30 Prof. ³
TOTALS	15 Sessions	15 Host Organizations	89 PWD 20 Family 70 Prof.

¹Thirty-two people attended this meeting both in person and online; however, an undetermined number of them participated in the conversation.

²An undetermined number of people attended this meeting both in person and online. Ten people participated in the conversation.

³Thirty people attended this meeting both in person and online; however, an undetermined number of them participated in the conversation.

ANALYSIS

Participants had the option to complete the CRA survey using a paper copy or keyboard entry using a web-based platform. Once all survey data were entered, they were downloaded to an Excel file where they were organized for analysis. The data were then analyzed using two statistical software programs, SPSS and R.

Statistical Tests

To further explore the needs of different groups who responded to the survey, the research team conducted statistical tests. Statistical tests check to find if any results are statistically significant and whether the significant difference found is real and not something that happened just by chance. Specifically, we used chi square analyses to determine if there are differences in the needs between individuals with IDD and their family members, between age groups, those with different disabilities, and those who had case management and did not.

It is important to note that chi-square tests only indicate that a difference exists; they do not specify where the difference lies. A significant result means the observed frequencies differ from what would be expected by chance. In other words, group membership appears to influence the choices individuals make. Examining the percentages or counts can provide additional insight into which options are preferred by each group. The results discussed below have a small p-value (less than 0.05 or 0.01), which suggests that the observed results are unlikely to have occurred by chance alone. Any of the p-values larger than this are excluded from the report because they indicate that the observed results could easily have occurred by chance.

Qualitative Data

Analysis of the listening session recordings and notes began by transcribing them into a text file. The text files were then uploaded to Dedoose, a qualitative data analysis platform. The research team coded and themed the listening session data highlighting statements that provided insight into the survey results.

ABOUT YOU

As mentioned above, a total of 258 individuals responded to the survey. The responses came from all regions of the state with the plurality from the northeast region (117, 45.3%) followed by the northwest region (59, 22.9%). The region with the smallest number of responses was the southeast region (12, 4.7%). Figure 1 above provides a pictorial description of the survey coverage. Table 5 below shows the demographic characteristics of the sample.

Of the 258 respondents, 137 were male (53.1%), 118 were female (45.7%), and three chose to self-identify (1.2%) (see Table 5). Respondents' ages ranged from about 1 year old to 76 years old with an average age of 31.1 (SD = 16.7). The largest age group was 25–34 years old (28.1%), while the smallest age group was 65–84 years old (3.1%). Of those who responded to the race question, a majority identified as White (79%), followed by Black or African American (7.4%), Hispanic (5.9%), Asian or Asian American (4.8%), and

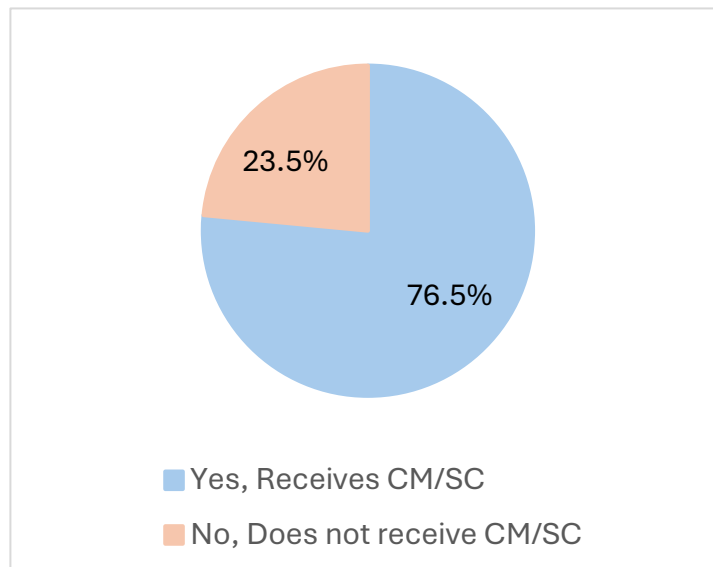
Table 5. Participant Demographics		
Gender		
	Frequency	Percent
Male	137	53.1
Female	118	45.7
Self-identify	3	1.2
Total	258	100.0
Age Categories		
Categories	Frequency	Percent
Under 5 yrs	10	3.9
5 - 17 yrs	45	17.6
18 - 24 yrs	32	12.5
25 - 34 yrs	72	28.1
35 - 44 yrs	42	16.4
45 - 64 yrs	47	18.4
65 - 84 yrs	8	3.1
Total	256	100.0
Missing	2	
Race		
	Frequency	Percent
White	214	79.0

Table 5. Participant Demographics		
Black or African American	20	7.4
Hispanic, Latino, Latinx, or Spanish Origin	16	5.9
Asian or Asian American	13	4.8
Prefer not to answer	1	0.4
American Indian or Alaska Native	3	1.1
A race/ethnicity not listed	4	1.5
Total	271	100
Disability		
	Frequency	Percent
Intellectual Disability	133	30.6
Autism Spectrum Disorder	109	25.1
Other	46	10.6
Seizure Disorder	39	9.0
Cerebral Palsy	37	8.5
Down Syndrome	22	5.1
Brain Injury	17	3.9
Limited or No Vision	16	3.7
Prader-Willi	5	1.2
Fetal Alcohol Syndrome	5	1.2
Severe or Profound Hearing Loss	5	1.2
Total	434	100

American Indian or Alaska Native (1.1%). There was a small group that identified that its race or ethnicity was not listed (1.5%). Individuals were allowed to select all that apply, so several individuals may have indicated multiple races (this can be seen in the total responses of 271, which is higher than the total respondents).

Intellectual disability (30.6%), autism spectrum disorder (25.1%), other (10.6%), and seizure disorder (9.0%) were the most common disabilities represented in the sample. The diagnoses with the lowest numbers were Prader-Willi (1.2%), Fetal Alcohol Syndrome (1.2%), and severe or profound hearing loss (1.2%) (Table 5). These diagnoses are not mutually exclusive; like the question about an individual's race, respondents were allowed to select all that apply, which means that several individuals have multiple diagnoses.

Figure 7. Case Management/Support Coordination



Among those who responded to the case management question, 192 received case management or support coordination (76.5%), while 59 did not (23.5%) (Figure 7).

Most of the respondents lived with their parents or another family member (53.5%), followed by living in a group home (12.0%), in an apartment or home with paid supports (10.5%), institutional care or nursing facility (8.1%), other (7.0%), independently without supports (7.0%), and in an apartment with unpaid supports (1.9%).

Table 6. Living Arrangement		
	Frequency	Percent
With parents/family	138	53.5
A group home/supervised residential setting	31	12.0
Apartment or home with paid supports	27	10.5
Institutional care or nursing facility	21	8.1
Other	18	7.0
Independently without supports	18	7.0
Apartment or home with unpaid supports	5	1.9
Total	258	100.0

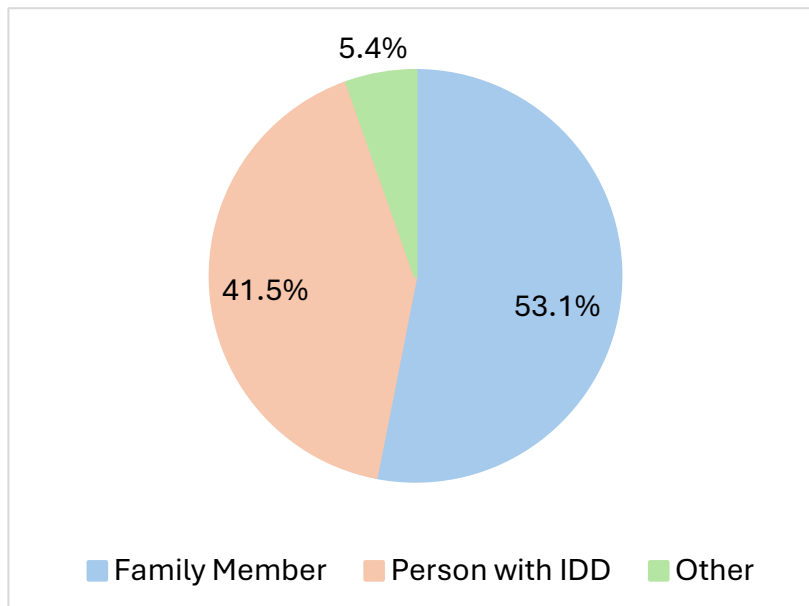
Out of the 258 responses in the primary day activity question, 69 identified that they were not employed (26.7%), followed by going to school (19.8%) and going to a day program (13.6%). The lowest number of respondents' primary day activity was pre-school (3.9%), retired (3.1%), and volunteering in the community (3.1%).

Table7. Primary Daytime Activity		
	Frequency	Percent
Not employed	69	26.7
School	51	19.8
Day program	35	13.6
Employed in a sheltered workshop	27	10.5

Table7. Primary Daytime Activity		
	Frequency	Percent
Employed without supports	26	10.1
Employed with supports	24	9.3
Pre-school	10	3.9
Retired	8	3.1
Volunteering in the community	8	3.1
Total	258	100.0

Finally, a slight majority of the surveys were completed on behalf of the person with an IDD by a parent or other family member (137, 53.1%). Nearly as many people with an IDD also completed the survey themselves (107, 41.5%). Thirteen people (5.4%) completed the survey in partnership with the person with IDD. If a family member or another person completed the survey, they were instructed to answer questions in the remaining sections as they related to the person with an IDD.

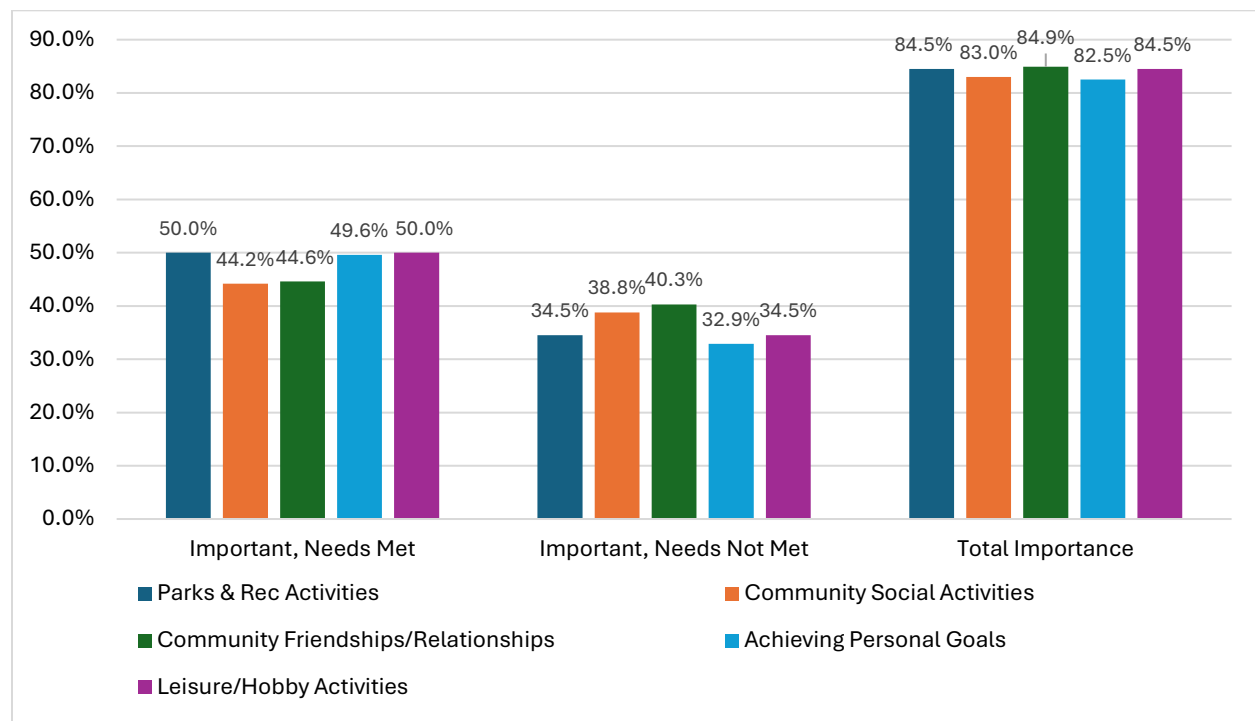
Figure 8. Who Completed the Survey?



WHAT YOU DO

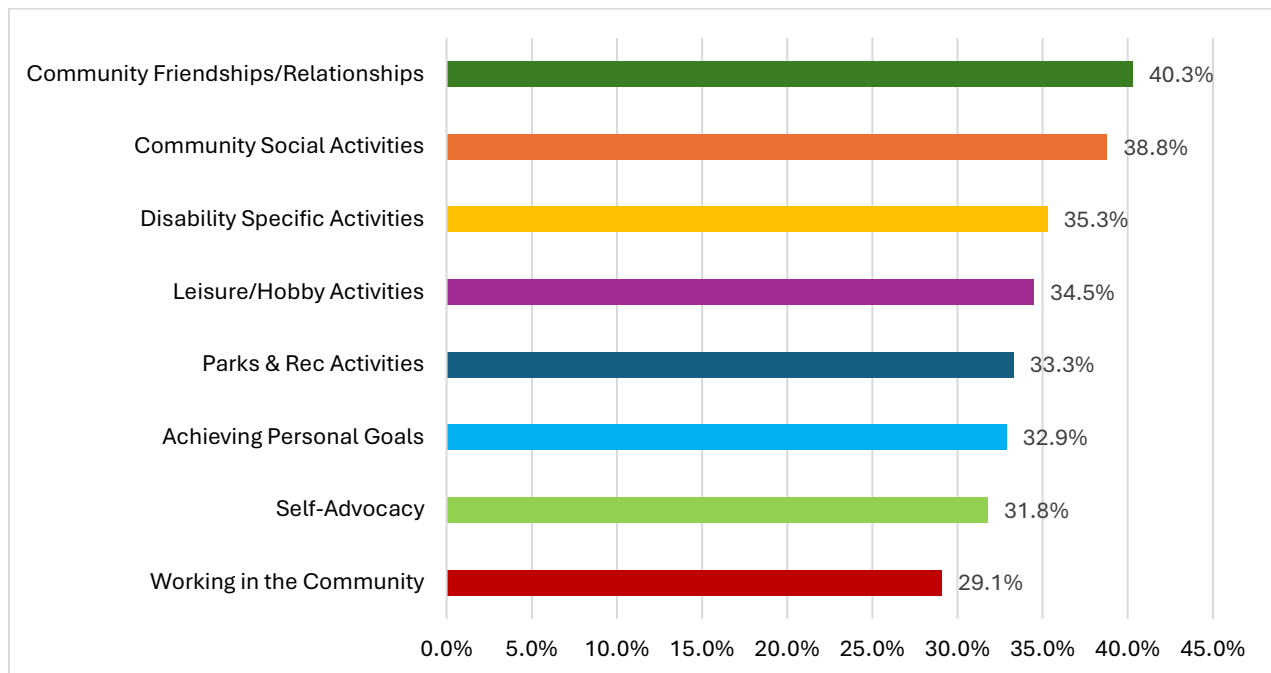
The purpose of Section 2 of the survey is to identify the daily life activities that were currently important to the respondents. As described above, people responded to each item in the survey using the following scale: 1) Not important: I **do not** want or need; 2) Important: my needs **are** met; and 3) Important: my needs **are not** met. The project team approached the data in several ways. First, the team looked at which items were identified as being most important overall. This was determined by summing the “*Important, my needs are met*” and “*Important, my needs are not met*” responses. As Figure 9 demonstrates, five items were important to more than 80% of the respondents. Among these, “Friendships or relationships with others in our community” was the most important (219, 84.9%), closely followed by “Leisure/Hobby Activities” (218, 84.5%) and “Parks and recreation activities” (218, 84.5%). “Social activities in your community” (214, 83%) and “Achieving personal goals” (213, 82.5%) were also very important to the respondents.

Figure 9. Most Important Daily Activities



The next level of analysis was to isolate those items that were “Important, but my needs are not met.” Figure 10 highlights the most important unmet needs identified by the respondents. Expanding the list to eight items reveals that “Disability specific activities, (e.g., People First)” (91, 35.3%), “Self-advocacy” (82, 31.8%), and “Working in the community” (75, 29.1%) were also important unmet needs.

Figure 10. Most Important Unmet Needs



Individuals with IDD vs. Family Members—Daily Activities

The first chi square analysis was used to explore the differences between answers provided by people with IDD (n=107) and the family members (n=137) who responded to the surveys. The chi square analysis demonstrates that there were statistically significant differences in the way individuals with IDD and family members responded to the issues listed. For example, family members were more likely than individuals to indicate that “Working in the community” was not important. At the same time, individuals with IDD were generally more likely to indicate that “Working in the community” was important. People with IDD were also more likely to indicate that “Volunteering in the community” was important. A look at “Disability specific activities” is interesting as family members were much more likely to indicate that this was not important. At the same time, there was a significant group of family members who indicated that it was important and the needs of their family members with IDD were not met. Another interesting data point is that family members were more likely than people with IDD to indicate that “Social activities in the community” were important daily activities. Additionally, family members were more likely than people with IDD to indicate that “Friendships or relationships with others in your community” was important.

Table 8. Daily Life Activities—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD n(%)	Family Members n(%)	Total N(%)	p-value
	1. Not important	20 (26.7)	55 (73.3)	75 (100)	<0.001

Table 8. Daily Life Activities—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD n(%)	Family Members n(%)	Total N(%)	p-value
Working in the community	2. Important: Needs are met	53 (60.9)	34 (39.1)	87 (100)	
	3. Important: Needs are not met	33 (45.2)	40 (54.8)	73 (100)	
Volunteering in the community	1.	23 (34.3)	44 (65.7)	67 (100)	<0.032
	2.	55 (54.5)	46 (45.5)	101 (100)	
	3.	24 (42.1)	33 (57.9)	57 (100)	
Disability specific activities (e.g., People First)	1.	16 (33.3)	32 (66.7)	48 (100)	<0.001
	2.	56 (57.7)	41 (42.3)	97 (100)	
	3.	29 (33.3)	58 (66.7)	87 (100)	
Social activities in your community	1.	16 (57.1)	12 (42.9)	28 (100)	<0.004
	2.	55 (51.9)	51 (48.1)	106 (100)	
	3.	30 (31.2)	66 (68.8)	96 (100)	
Friendship or relationship with others in your community	1.	14 (77.8)	4 (22.2)	18 (100)	<0.001
	2.	51 (47.7)	56 (52.3)	107 (100)	
	3.	30 (29.7)	71 (70.3)	101 (100)	

Age Group Differences—Daily Activities

The next area of comparison was between age groups. Age groups were formed based on the U.S. Census Bureau’s seven groups: Under 5 years, 5-17 years, 18-24 years, 35-44 years, 45-64 years, and 65-84 years old. When looking at daily activities important to respondents’ lives right now, results showed the following issues had significant differences: Working in the community, Working in a summer employment, Volunteering in the community, Leisure/hobby activities, Membership in organizations or clubs (like 4H, Scouts, Lions), Disability specific activities (e.g., People First). In other words, different age groups had different priorities in daily activities. For example, when looking at the issue of “Working in the community,” about 28% of individuals who indicated that this was not important were 5-17 years old. In contrast, about 33% of those who considered it important and had their needs met, and about 32% of those who considered it important but had unmet needs, were 25-34 years old. This shows that “Working in the community” was a priority for those who were 25-34 years old, but not for those who were 5-17 years old. In fact, as Table 16 in Appendix A demonstrates, people who were 25-34 years old prioritized nearly all of the items more than the other age groups. The two exceptions were for people 5-17 years old who indicated that “Membership in organizations or clubs” and “Disability specific activities” were important and their needs were unmet.

Disability Groups—Statistical Significance of Daily Activities

We also conducted an analysis to identify statistically significant differences between disability groups. In this comparison, the four largest disability groups were chosen for comparison: intellectual disability, autism, seizure disorder, and other. Since individuals can select more than one disability in the survey, an individual could be counted twice in this analysis. This could bias the chi-square results meaning the results are not as straightforward to explain.

When looking at daily activities important to their life right now, “Achieving personal goals” was the only issue with a significant difference. First, respondents with intellectual disabilities represented 65% of people who indicated that achieving personal goals is not important. Meanwhile, nearly 41% of people who consider this as important with met needs were also people with intellectual disabilities; however, about 43% of people who consider this important with unmet needs were individuals with autism (see Appendix A, Table 17).

Case Management / Support Coordination—Daily Activities

In this comparison, differences were explored between those who had case management versus those who did not. When looking at issues related to daily activities, the following had significant differences: “Working in a sheltered workshop,” “Social activities in your community,” and “Self-advocacy.” Those with case management were significantly more likely to respond to each item, indicating that they had stronger opinions about each item than people who did not receive case management. For example, 70% who considered working in a sheltered workshop as *not* important are those with case management; however, about 90% of those who considered this item “important with met needs” and about 84% considered who considered it “important with unmet needs” were also those with case management (See Appendix A, Table 18).

Challenges to Getting a Job

Another set of questions related to daily activities was specific to challenges to getting a job. The participants were asked to choose all responses that applied to them (see Table 9). Because people were asked to choose all items that applied, the total number of responses (586) is more than the number of people who completed the survey (258). Percentages in the table are based on the number of people who completed the survey, not the number of responses. The first notable result of this inquiry is that nearly 37% of the respondents indicated that this topic did not apply to them. For those to whom the question did apply, “Transportation” was the greatest challenge to getting a job (61, 23.6%). Forty-five (17.4%) respondents indicated that they worried getting a job would affect their benefits (e.g., SSI, SSDI, etc.). Lastly, knowing what is available was also a challenge for 30 (11.6%) of the respondents.

Table 9. Challenges to Getting a Job		
Responses	N	Percent of Cases
Does not apply	95	36.8
Not knowing what I need	19	7.4
Not knowing what is available	30	11.6
Service I need is not available	17	6.6
Being on a waitlist	18	7.0
Service is available, but level of support is insufficient	25	9.7
Location of service providers	18	7.0
Cost of service	7	2.7
Impact on benefits (e.g., SSI, SSDI, etc.)	45	17.4
Not having technology (i.e., internet, broadband, etc.)	14	5.4
Not knowing who to ask about resources	24	9.3
Quality of service (reliability, consistency)	22	8.5
Transportation	61	23.6
Other	37	14.3
Total	432	167.3

Some challenges around employment were expressed during the listening sessions. This included transportation to a job and needing a new job to secure additional income. One listening session participant identified the limitations due to transportation,

“I’m sorry about that. What I was going to say is, the reality is sometimes we just have to job-develop to what’s possible, which means it’s maybe not the best job. Like, if transportation was no barrier, then there might be a different choice that’s made.”

Even people who found a job discussed some of the challenges they experience. One person talked about the challenges with having a full-time job when she said, “It’s just hard with how many hours I have to work at Walmart just to make ends meet and get where I need to be at.”

During two of the listening sessions with individuals with IDD who worked in a sheltered workshop and parents of people who worked in the workshop and direct service providers, the project team heard how—for some—the workshop helped solve some of the challenges listed above.

“Many people can’t function in competitive work environments. And she flourishes in the sheltered workshop where she’s able to work, um, at her own ability and pace with support. And then it can be an environment where she finds success at her own level and has a sense of purpose.”

Another parent reflected on the stories they hear from people in sheltered workshops,

“Um. Uh, there's so many people I hear about these stories. Everybody says the same thing. It's, you know, we've tried to approach. We've tried minimum wage

employment. It's not been the right fit. We have found Shelter Workshop, where the person is able to work at their own pace with help with consideration and, um, most importantly, not jeopardize their government benefits.

You know, the problem is know if they can function in a minimum wage environment, um, with or without support ... minimum wage does not allow them to pay for all the supports they may need, whether it's, you know, a medical support or a staffing support in my sister's case where she needs some staffing to help her get through some daily, you know, activities of life.

Um, and it's really great that so I always come back to it's nice to have a shelter workshop option because, I mean, it's not just nice, it's critical because it allows a tailored response for an individual, um, minimum wage employment, uh, may be great for a lot of people, but it's also, uh, frankly, impossible for many others. And the sheltered workshop allows them to go somewhere where they can be successful, have purpose in life and, you know, contributed to the level they can contribute.”

In contrast, the workshop experience was not a long-term solution for everyone. As the person quoted below reflected:

Participant: “Well, I'd like to see about getting another job, and I have started looking into it. Probably about..., probably about a week ago. Yeah, because right now, I do work at the sheltered workshop. But I'd like to get out of the sheltered workshop. I'm gonna think about it that way. Seeing that within the Next five years.”

Interviewer: “And what are you looking for?”

Participant: “Just any, any job I can do that, so I can make more income.”

Key Points

- Community engagement activities at many levels were the most important unmet needs related to daily activities.
- Family members were more likely than individuals to indicate that “Working in the community” was not important.
- Individuals with IDD were generally more likely to indicate that “Working in the community” was important.
- Respondents with intellectual disabilities were significantly more likely to indicate that “Achieving personal goals” was not important to them.
- People with autism were significantly more likely to indicate that “Achieving personal goals” was important to them and they had unmet needs.
- “Transportation” is the biggest challenge to getting a job.

LIFE TRANSITIONS

The final set of questions related to the “What You Do” section of the survey, which asked about life transitions. Figure 11 highlights the four most common responses. Three of the most important items revolved around planning. The fourth item recognizes the importance of building “Independent living skills.”

Figure 11. Most Important Life Transitions Needs

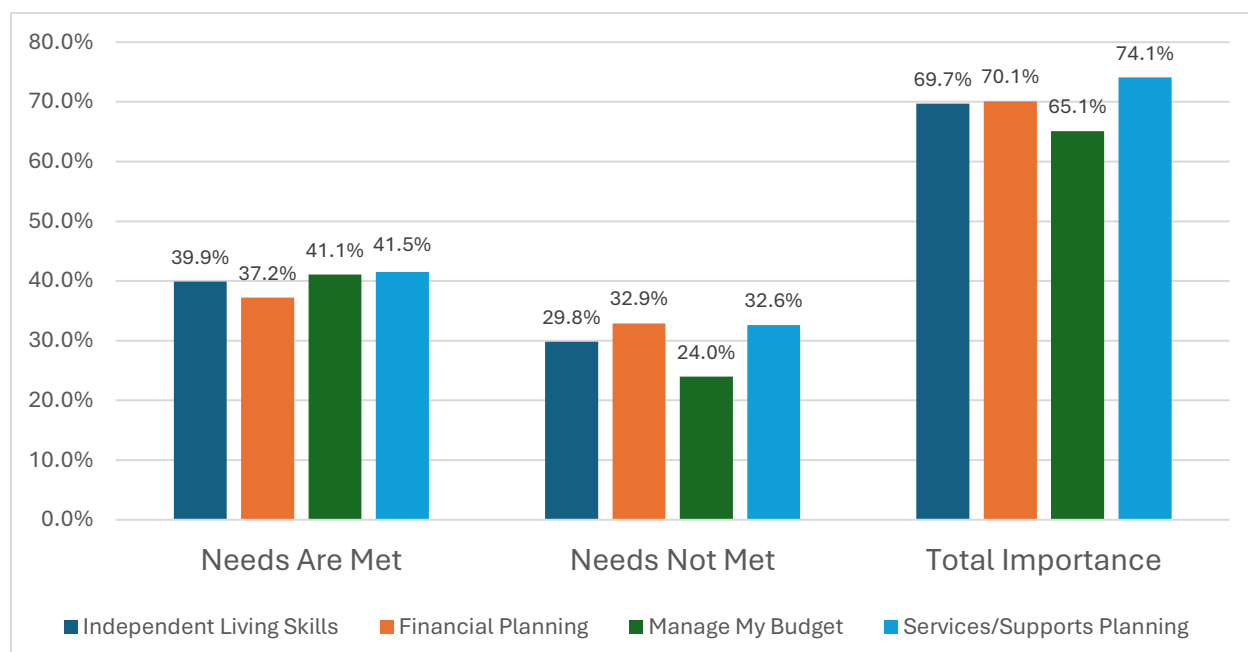
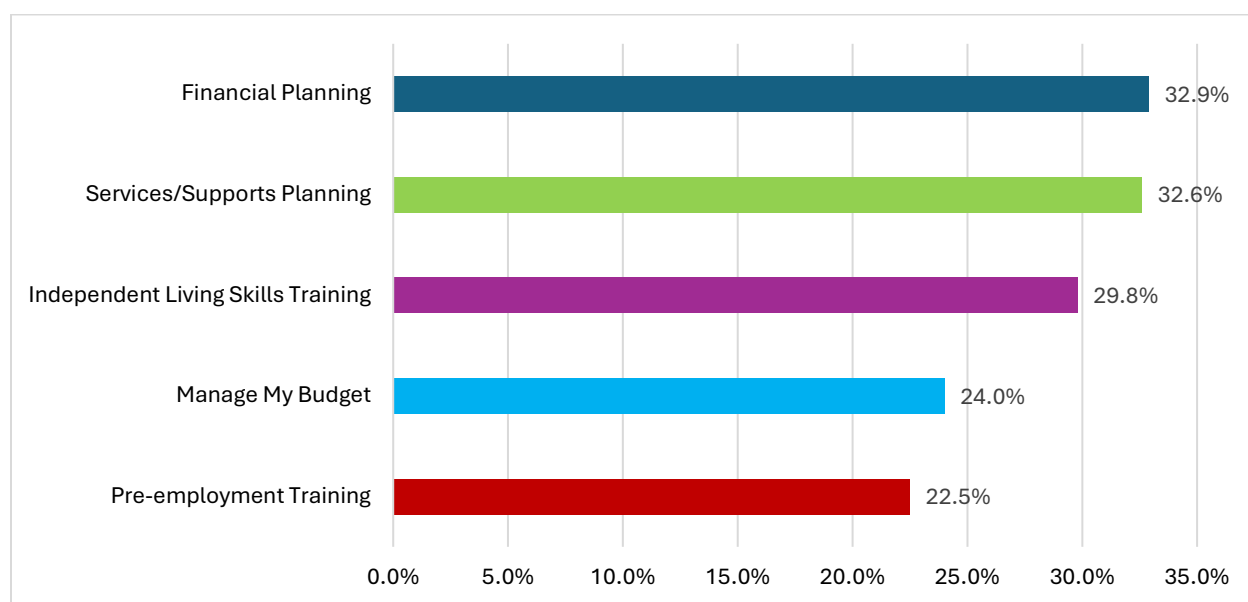


Figure 12. Most Important Unmet Life Transitions Needs



In terms of unmet life transition needs, Figure 12 displays those items the respondents thought were most important. As a group, they point to the need for planning resources and training that will ensure that individuals with IDD are prepared for adult living.

Individuals with IDD vs. Family Members—Life Transitions

The project team examined life transition responses using the chi square analysis described above to establish which items were significantly different regarding the needs expressed by individuals with IDD and their family members and between age groups. There were no statistically significant differences found between those with different disabilities or case management recipients.

The first chi square analysis was used to explore the differences between answers provided by people with IDD (n=107) and the family members (n=137) who responded to the surveys. The analysis demonstrates that there were statistically significant differences in the way individuals with IDD and family members responded to the issues listed. As Table 10 indicates, family members were statistically more likely to feel that “Planning for transition into early childhood education” was important. Perhaps not surprisingly, family members were also more inclined to feel that “Planning for transition from school to work/adult life” was important. Family members were also statistically more likely to indicate that “Adult education (GED/continuing education/college education) was not important. This contrasts with individuals with IDD who indicated that adult education was important to them, but they did not need more information. Family members were also statistically more likely to indicate that services/supports planning (e.g. Medicaid, Medicare, etc.) was important and their needs were not met.

Table 10. Transitions—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD	Family Members	Total	p-value
Planning for transition into early childhood education (K-12)	1. Not important	72 (47.7)	79 (52.3)	151 (100)	<0.034
	2. Important: Needs are met	12 (27.3)	32 (72.7)	44 (100)	
	3. Important: Needs are not met	6 (31.6)	13 (68.4)	19 (100)	
Planning for transition from school to work/adult life	1.	56 (46.7)	64 (53.3)	120 (100)	<0.001
	2.	24 (54.5)	20 (45.5)	44 (100)	
	3.	9 (18.4)	40 (81.6)	49 (100)	
Adult education (GED/continuing education/college education)	1.	47 (35.6)	85 (64.4)	132 (100)	<0.014
	2.	23 (60.5)	15 (39.5)	38 (100)	
	3.	22 (50.0)	22 (50.0)	44 (100)	
Services/supports planning (e.g.	1.	22 (55.0)	18 (45.0)	40 (100)	<0.001
	2.	48 (48.5)	51 (51.5)	99 (100)	
	3.	21 (25.9)	60 (74.1)	81 (100)	

Table 10. Transitions—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD	Family Members	Total	p-value
Medicaid, Medicare, etc.)					

Age Group Differences—Life Transitions

When looking at issues related to life transitions, the following had significant differences: “Planning for transition into early childhood education (K-12)”, “Planning for transition for school to work/adult life,” “Pre-employment training”, “Adult education (GED/continuing education/college education)”, “Services/supports planning (e.g. Medicaid, Medicare, etc.)”, “Managing a budget,” “Independent living skills training (grocery shopping, cooking, home management)”, and “Alternatives to guardianship.” Like daily activities, different age groups prioritized different categories in life transitions (see Appendix B, Table 19). For example, about 33% of individuals who said planning for transition into early childhood education was not important were ages 25-34 years old. Meanwhile, about 33% of individuals who considered this important and had their needs met and about 42% who considered it important but had unmet needs were 5-17 years old. These findings reflect the different needs in life transitions for different age groups. Some other interesting findings for those who were 5-17 years old is that they were more likely to believe that “Pre-employment training” was important and their needs were not met. At the same time, they were significantly more likely to indicate that “Independent living skills training” was not important, and they did not want or need it.

As with the Daily Life activities, those who were between 25 and 35 years old often had statistically significant differences with the other age groups (see Appendix B, Table 19). Most interestingly, they were significantly more likely to view “Manage my budget,” “Independent living skills training,” and “Alternatives to guardianship” as important. Lastly, people who were between the ages of 45 and 64, were most likely to indicate that “Alternatives to guardianship” was not important and they did not want or need it. The quote below highlights this sentiment.

“And I feel like the more things we can do as individuals on our own, the more independent we feel.

That's just my opinion of, like say if I go to the doctor all by myself and I get everything done all by myself that makes me feel good. And it shows that I can do this, and I don't need help. Yeah. I mean, I always like to have help. But like, if I were to not have help anymore. What would I do? That way I'm teaching myself that I can do this. And it makes, it makes me feel important.”

Case Management / Support Coordination—Life Transitions

When looking at life transitions, the following issues showed significant differences: “Services and supports planning (e.g. Medicaid, Medicare, etc.)”, “Managing my budget,”

“Financial planning”, and “Alternatives to guardianship.” Again, those with case management had a majority in each of these areas (see Appendix B, Table 20).

Challenges to Transition Support

The respondents identified multiple challenges related to transitions. These transitions may include going from school to work, changing living situations, or retirement. The greatest challenge identified was “Not knowing what is available” for transition support (88, 34.1%). The second leading challenge was “Transportation” support (79, 30.6%). Other highly ranked challenges included “Not knowing what I need,” (57, 22.1%) and “Quality of services (reliability, consistency)” (56, 21.7%). Table 8 below provides a complete list of the challenges to transition support.

Table 11. Challenges to Transition Support		
Responses	N	Percent of Cases
Does not apply	59	22.9
Not knowing what I need	57	22.1
Not knowing what is available	88	34.1
Service I need is not available	49	19.0
Service is available, but level of support is insufficient	41	15.9
Location of service providers	47	18.2
Cost of service	49	19.0
Not knowing who to ask about resources	43	16.7
Quality of services (reliability, consistency)	56	21.7
Transportation	79	30.6
Other	18	7.0
Total	586	227.2

During the listening sessions, individuals with IDD, family members, and professionals identified additional challenges with transition. For example, one parent noted the exhaustion that overtakes many parents:

“They’re going to gravitate toward the path of least resistance because, frankly, they’re tired. By the time their child reaches adulthood, families have spent years advocating in the education system. There’s only so much they have to give.”

As Table 11 above indicates, one of the major challenges that people experience related to transition supports is transportation to new opportunities. The quote below is from a parent who is also a service professional in the greater Kansas City area.

“Because of all the transfers—you take this bus, then you have to stop, transfer, and get on that bus. So being able to navigate that and know how to use it safely is difficult. Again, safety is a big concern for a lot of families and their loved ones because we all hear the horror stories.”

“I mean, in Kansas City there's an abundance of transportation, but it's not safe. We have free public transportation, which if you're in a rural area the idea of that sounds amazing—until one of your clients gets a knife pulled on them on the bus. So, you know, there are a lot of different elements of transportation that we deal with in the metro area.”

Key Points

- Planning resources and training about transition were the most important unmet needs (see Figure 12).
- Family members were significantly more inclined to feel that “Planning for transition from school to work/adult life” was important.
- Family members were statistically more likely to indicate that “Adult education (GED/continuing education/college education) was not important.
- Individuals with IDD who indicated that adult education was important to them, also indicated they did not need more information.
- Family members were more likely to indicate that services/supports planning (e.g. Medicaid, Medicare, etc.) was important and their needs were not met.
- The greatest challenges to transition support were not knowing what is available and transportation (see Table 11).

WHERE YOU LIVE

Section three of the survey focused on the living situation of people with IDD who participated in the CRA. The purpose of this section was to discover which living arrangements were most important to the respondents and where they believed their needs were not being met. Figure 13 demonstrates very clearly that the three most important living situations overall were “Feeling safe at home” (198, 76.7%), “Having privacy in your home” (201, 77.9%), and “Feeling safe in your community” (210, 81.4%). Another important need related to living situation is “Living with parents/family” (155, 60.1%); however, an important point to recognize is that these four needs were classified as “important,” but the respondents’ needs were met. So, while they are important, these issues do not require immediate action.

Figure 14 highlights the most important unmet living arrangement needs. For example, nearly a quarter of the respondents (61, 23.6%) indicated that living in an apartment or home with paid supports was important, but their needs were not met. Other respondents expressed an interest in living independently without supports (51, 19.8%). Safety was an important unmet need for the participants. For example, “Feeling safe in your community” was also third highest unmet need. In addition to this, people indicated an unmet need related to “Feeling safe at home” and “Having privacy in your home.”

Figure 13. Most Important Living Arrangements

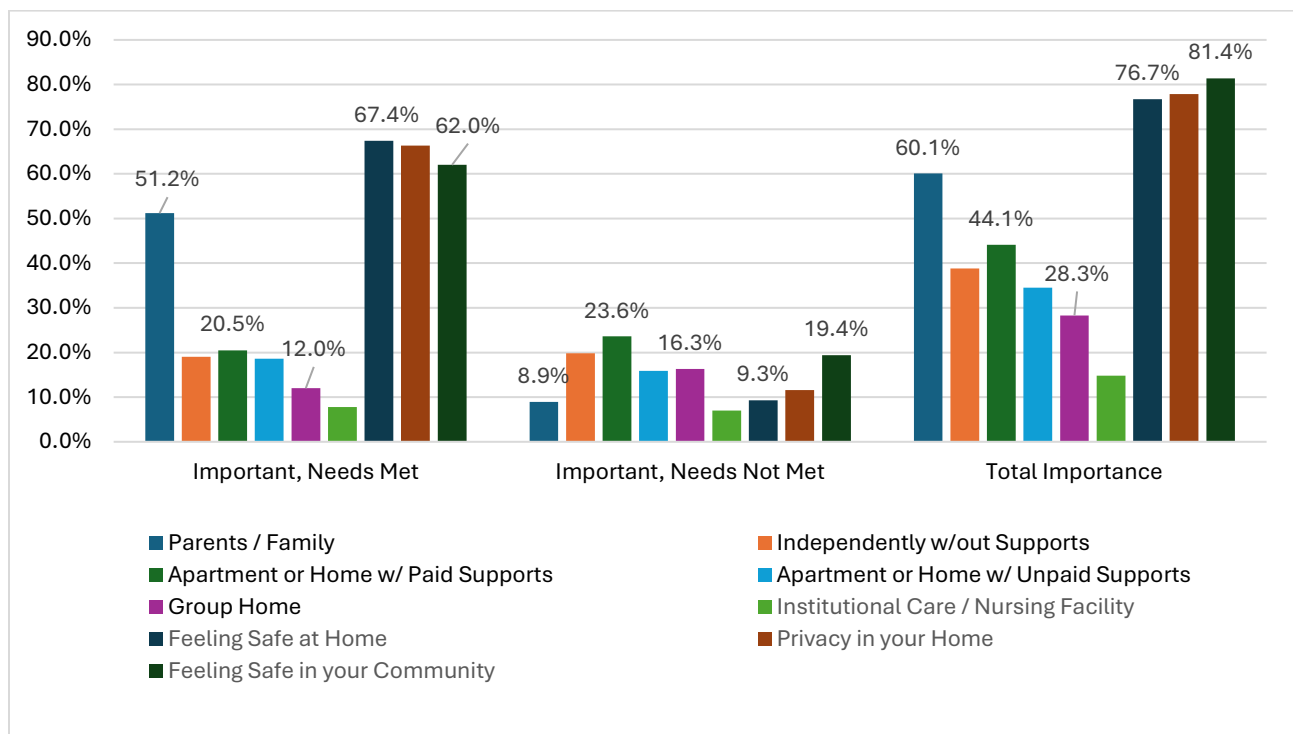
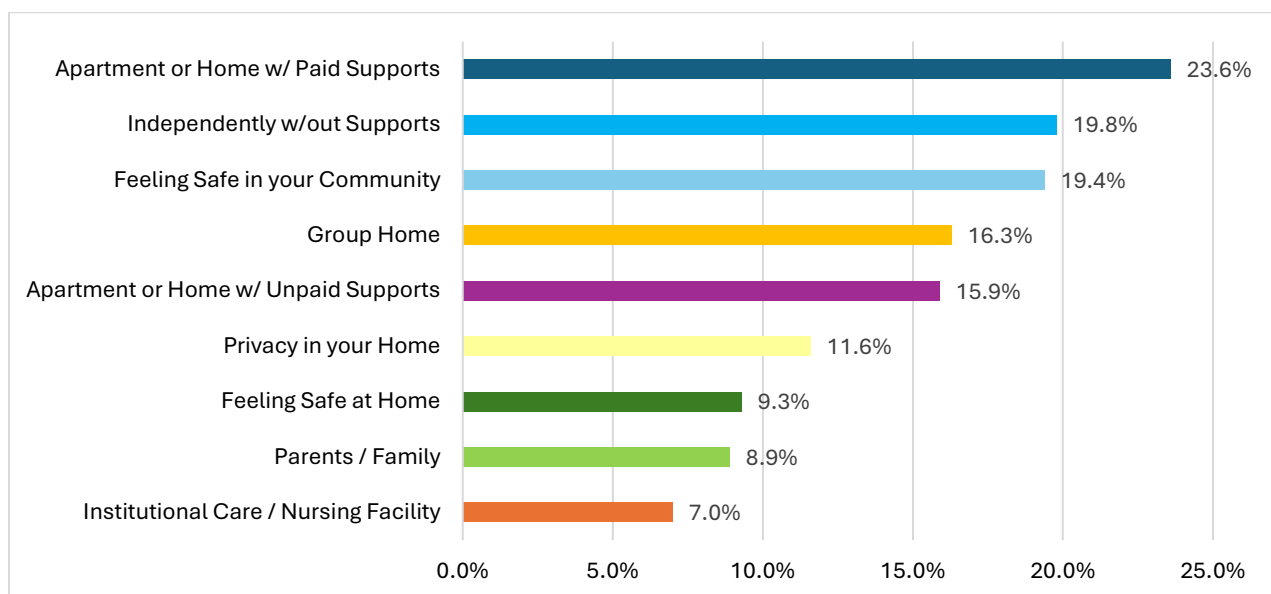


Figure 14. Most Important Unmet Living Needs



Challenges to Obtaining Needed Living Options

Survey participants had the opportunity to highlight the challenges to obtaining the living options they wanted. Slightly over a third of the respondents (88, 34.1%) indicated that they did not experience challenges. “Transportation” (57, 22.0%) was the most often cited

challenge. As with previous sections, “Not knowing what is available” was one of the leading challenges. Another leading challenge to obtaining needed living options was “Cost of service.”

Table 12. Challenges to Obtaining the Living Options that you Need		
Responses	N	Percent of Cases
Does not apply	88	34.1
Not knowing what I need	27	10.5
Not knowing what is available	46	17.8
Service I need is not available	34	13.2
Service is available, but level of support is insufficient	38	14.7
Location of service providers	38	14.7
Cost of service	46	17.8
Not knowing who to ask about resources	32	12.4
Quality of services (reliability, consistency)	40	15.5
Transportation	57	22.0
Other	16	6.2
Total	462	178.9

Challenges related to housing were not limited to the items listed in Table 12. The extensive quote below highlights challenges experienced by a family in which both the individual with IDD and his parents are aging.

“They’re being very gracious about it. But we just had a hearing to kind of rethink the— is he eligible for a waiver so he could get housing residential? And they did approve him. But there’s no funding. So, my parents are crammed in this little apartment trying to—trying to move from what they had. You know, they had a home, and then they had an efficiency apartment in the home next to them. So, they had some space. But basically, they’re back to like parenting at a level they aren’t really looking to do right now, and they really just need to be able to have a little bit of empty nest, old age, you know?”

Individuals with IDD vs. Family Members—Living Arrangements

As in the previous sections, the project team used a chi square analysis to discover those areas where there were statistically significant differences in the ways individuals and family members answered the questions. As it pertains to living arrangements, there were six areas of difference (see Table 13). People with disabilities were significantly more likely to indicate that “Living with parents/family” was not important. Family members, on the other hand, indicated that this issue was important and their needs were met. Another area of difference was related to “Living independently without supports.” Family members were more likely to say that this was not an important living arrangement. At the same time, a sub-group of parents were more likely to indicate that it was important, but their needs were not met. “Living in an apartment or home with paid supports” was an area that family

members were more likely to consider unimportant and individuals with disabilities were more likely to indicate that it was important, but their needs were met. Family members felt that “Living in a group home/supervised residential setting” was not an important living arrangement. At the same time, a subset of parents was more likely to indicate that it was important but their needs were not met. Family members very clearly indicated that “Living in institutional care or nursing facility” was not important. Both individuals with IDD and family members believed that “Feeling safe in your community” was important but individuals were more likely to indicate that their needs were unmet whereas family members were more likely to say that their needs were met.

Table 13. Living Arrangement—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD	Family Members	Total	p-value
Living with parents/family	1. Not important	42 (65.6)	22 (34.4)	64 (100)	<0.001
	2. Important: Needs are met	35 (27.1)	94 (72.9)	129 (100)	
	3. Important: Needs are not met	13 (59.1)	9 (40.9)	22 (100)	
Living independently without supports	1.	23 (34.3)	44 (65.7)	67 (100)	<0.001
	2.	55 (54.5)	46 (45.5)	101 (100)	
	3.	24 (42.1)	33 (57.9)	57 (100)	
Living in an apartment or home with paid supports	1.	34 (32.7)	70 (67.3)	104 (100)	<0.001
	2.	31 (64.6)	17 (35.4)	48 (100)	
	3.	24 (40.7)	35 (59.3)	59 (100)	
Living in a group home/supervised residential setting	1.	64 (43.5)	83 (56.5)	147 (100)	<0.001
	2.	19 (70.4)	8 (29.6)	27 (100)	
	3.	9 (21.4)	33 (78.6)	42 (100)	
Living in institutional care or nursing facility	1.	65 (37.1)	110 (62.9)	175 (100)	<0.002
	2.	15 (78.9)	4 (21.1)	19 (100)	
	3.	7 (41.2)	10 (58.8)	17 (100)	
Feeling safe in your community	1.	5 (35.7)	9 (64.3)	14 (100)	<0.025
	2.	57 (37.5)	95 (62.5)	152 (100)	
	3.	29 (59.2)	20 (40.8)	49 (100)	

Age Group Differences—Living Arrangement

When looking at issues related to living arrangements, the following issues had significant differences: “Living with parents/family”, “Living independently without supports,” “Living in an apartment or home with paid supports,” “Living in an apartment or home with unpaid supports (e.g. family/friends),” and “Living in a group home/supervised residential setting.” Age clearly played a role in prioritizing the different issues under living arrangements. About 32% of those who considered living with parents or family as not important were 45-64 years old. On the other hand, 29% who considered this important with their needs met and

39% who considered this important with unmet needs were 25-34 years old. Respondents who were between 5 and 17 years of age were much more likely to say that multiple living arrangements were not important. These include items such as “Living independently without supports,” “Living in an apartment or home with paid supports,” “Living in an apartment or home with unpaid supports.” Table 21 in Appendix C highlights the other categories that were significant. As was the case in previous sections, people who were 25-34 years old were more likely to have significantly different perspectives than people from the other age groups.

Case Management/Support Coordination Differences—Living Arrangements

Table 22 in Appendix C highlights the differences between those who receive case management and those who do not. When looking at issues related to living arrangements, only “Living in an apartment or home with paid support” had significant differences between those who received case management and those who did not. The data indicate that those who received case management had much stronger feelings about this topic.

Key Points

- Living in an apartment or home with paid supports was an important unmet need.
- Living independently without supports was an important unmet need for many of the respondents.
- Information about safety in their homes and community was an important unmet need for the participants.
- The greatest challenges to obtaining the living options participants wanted were: 1) Transportation; and 2) Not knowing what was available.
- People with disabilities were significantly more likely to indicate that “Living with parents/family” was not important. Family members, on the other hand, indicated that this issue was important and their needs were met.
- “Living in an apartment or home with paid supports” was an area that family members were more likely to consider unimportant and individuals with disabilities were more likely to indicate that it was important, but their needs were met.
- Both individuals with IDD and family members believed that “Feeling safe in your community” was important, but individuals were more likely to indicate that their needs were unmet whereas family members were more likely to say that their needs were met.

FUTURE NEEDS

The purpose of Section 4 of the survey was to identify the future needs (next five years) that were most important to the respondents. In terms of total importance, there were multiple items that 70% of the people or more identified as important future needs (see Figure 15). Social and recreational activities were among the most important. These included “Community social activities,” “Community friendships,” and “Leisure/hobby activities.” Two items, “Privacy in your home” and “Feeling safe in your community,” were important but the respondents did not need information. “Community social activities” and “Achieving personal goals” were among the most important topics about which the respondents needed more information.

Figure 15. Most Important Future Needs

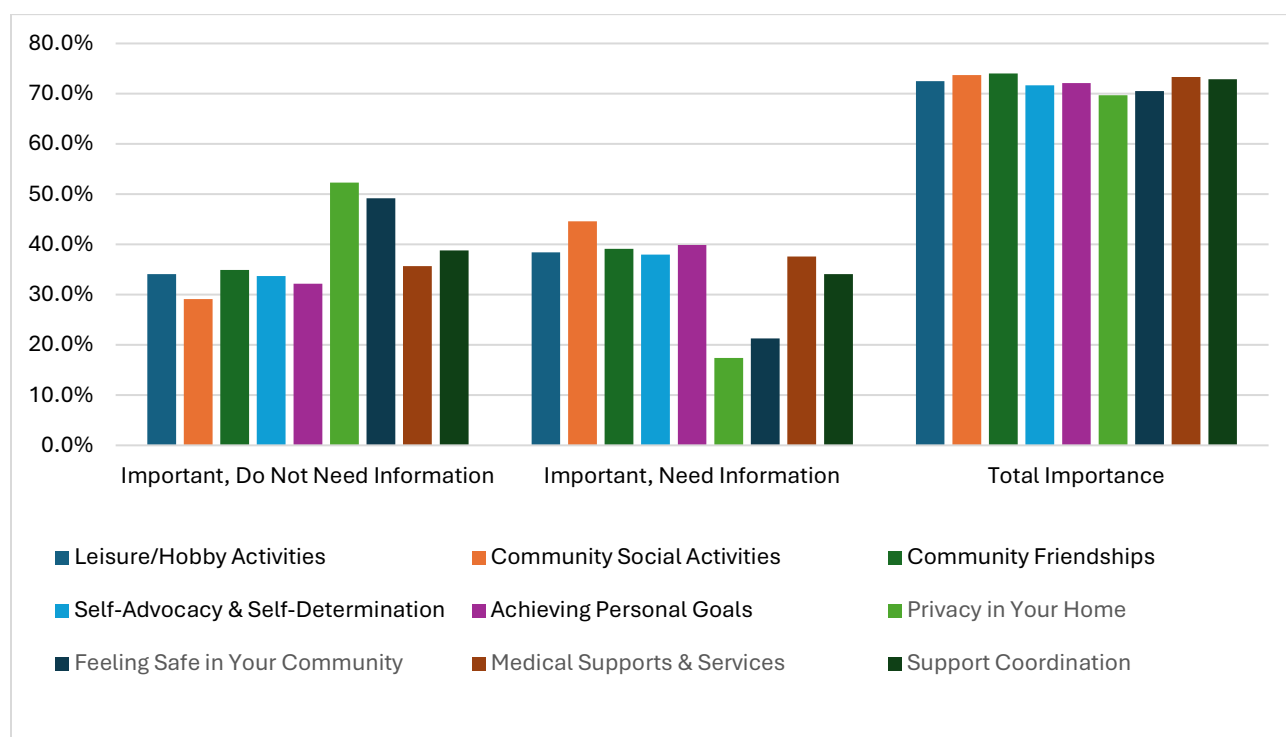
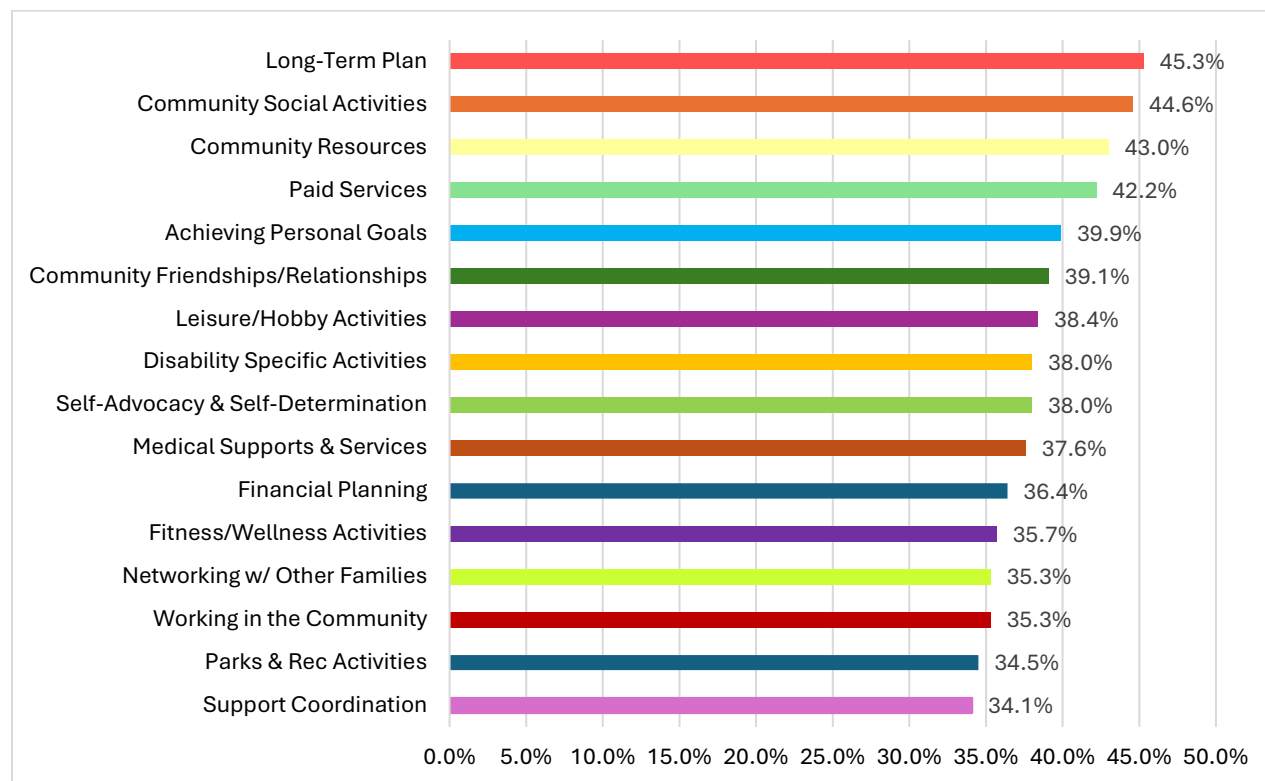


Figure 16 depicts those items about which the respondents wanted more information. Each of the items received interest from more than a third (33.3%) of the respondents. A few themes are present in these results, most notably community engagement. At least five of the items directly point to the importance of social and employment opportunities in the community, including “Community social activities,” “Community friendships/relationships,” “Working in the community,” and “Parks & recreation activities.” Another important area of needed information was focused on long-term planning and preparation, including “Long-term plan,” “Financial planning,” and “Achieving personal goals.” Another area of need included information about medical and wellness activities. Finally, there is an emphasis on information about advocacy opportunities and disability-specific activities.

Figure 16. Most Important Needs for Additional Information in Next Five Years



The short quote below from a person with IDD poignantly highlights the importance of the unmet social and community engagement needs.

Interviewer: Anything else that could happen to make your life better?

Participant: Getting a chance to meet more people.

Individuals with IDD and family members highlighted “Paid services” and “Long-term planning” as an important need across all of the sections of the survey. Many of these types of needs are directly related to Medicaid benefits. Below are some quotes from people who participated in the listening sessions and talked about Medicaid and long term services and supports.

“Thinking of benefits planning in particular—okay, we’ve got our WIPA providers, we’ve got our community mental health providers, we’ve got it available under DD funding. But what if you don’t have a waiver, and you’re not connected with a community mental health provider, and you’re not wanting to work and get off of your benefits?”

Another participant expressed the difficulty navigating the process,

“And I would agree—Medicaid’s a nightmare. If I hadn’t just decided to basically make it my part-time job to just go with them and help them and go and sit in an

office until we figured out everything we needed to figure out to get it started here, he would probably still be waiting to get Medicaid. So, we have had some things that came through, but it was just because I was willing to advocate and help my parents navigate it. Otherwise, I think they'd still be stuck. So that's where I'm coming from.”

Many participants reflected on the need for a more streamlined process when it came to Medicaid, highlighting concerns of delay in receiving benefits, delayed communication, and concerns about funding cuts.

Individuals with IDD vs. Family Members—Statistical Significance

As in the previous sections, the project team used a chi square analysis to discover those areas where there were statistically significant differences in the ways individuals and family members answered the questions. As it pertains to future needs, there were 15 areas of significant difference (see Table 14). Family members were significantly more likely to indicate that “Working in the community” and “Working in summer employment” were not important. Family members were also more likely to say that any living situation outside the family home was not important. On the other hand, people with IDD were significantly more likely to indicate that living with parents or family was not important. Family members indicated that they needed more information about various types of services and supports the person with IDD may need in the future. These included “Access to paid services,” “Occasional out-of-home support (respite),” and “Personal care assistance.” Interestingly, families were more likely to say they needed more information about “Friendships or relationships with others in your community.”

Table 14. Future Needs—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD	Family Members	Total	p-value
Working in the community	1. Not important	16 (25.4)	47 (74.6)	63 (100)	<0.001
	2. Important: Will not need additional info.	34 (61.8)	21 (38.2)	55 (100)	
	3. Important: Will need additional information	39 (45.9)	46 (54.1)	85 (100)	
Working in summer employment	1.	44 (38.6)	70 (61.4)	114 (100)	<0.017
	2.	23 (65.7)	12 (34.3)	35 (100)	
	3.	20 (41.7)	28 (58.3)	48 (100)	
Disability specific activities (like People First)	1.	11 (27.5)	29 (72.5)	40 (100)	<0.002
	2.	41 (60.3)	27 (39.7)	68 (100)	
	3.	38 (40.9)	55 (59.1)	93 (100)	
Friendships or relationships with others in your community	1.	12 (63.2)	7 (36.8)	19 (100)	<0.016
	2.	44 (51.2)	42 (48.8)	86 (100)	
	3.	33 (34.4)	63 (65.6)	96 (100)	

Table 14. Future Needs—Individuals with IDD vs. Family Members					
Issue	Importance Rating	Individ. w/ IDD	Family Members	Total	p-value
Planning for transition from work to retirement	1.	41 (36.9)	70 (63.1)	111 (100)	<0.014
	2.	17 (60.7)	11 (39.3)	28 (100)	
	3.	28 (57.1)	21 (42.9)	49 (100)	
Retirement supports	1.	39 (35.1)	72 (64.9)	111 (100)	<0.001
	2.	17 (58.6)	12 (41.4)	29 (100)	
	3.	31 (64.6)	17 (35.4)	48 (100)	
Living with family/parents	1.	40 (60.6)	26 (39.4)	66 (100)	<0.001
	2.	29 (31.2)	64 (68.8)	93 (100)	
	3.	19 (52.8)	17 (47.2)	36 (100)	
Living independently without supports	1.	33 (36.3)	58 (63.7)	91 (100)	<0.014
	2.	25 (64.1)	14 (35.9)	39 (100)	
	3.	28 (45.9)	33 (54.1)	61 (100)	
Living in an apartment or home with supports	1.	32 (41.6)	45 (58.4)	77 (100)	<0.024
	2.	25 (65.8)	13 (34.2)	38 (100)	
	3.	31 (40.8)	45 (59.2)	76 (100)	
Living in a group home/supervised residential setting	1.	48 (44.0)	61 (56.0)	109 (100)	<0.001
	2.	23 (71.9)	9 (28.1)	32 (100)	
	3.	16 (31.4)	35 (68.6)	51 (100)	
Living in institutional care or nursing facility	1.	57 (39.6)	87 (60.4)	144 (100)	<0.001
	2.	19 (86.4)	3 (13.6)	22 (100)	
	3.	12 (48.0)	13 (52.0)	25 (100)	
Access to paid services	1.	12 (41.4)	17 (58.6)	29 (100)	<0.001
	2.	42 (66.7)	21 (33.3)	63 (100)	
	3.	33 (32.0)	70 (68.0)	103 (100)	
Occasional out-of-home support (respite)	1.	38 (50.7)	37 (49.3)	75 (100)	<0.002
	2.	27 (60.0)	18 (40.0)	45 (100)	
	3.	20 (28.6)	50 (71.4)	70 (100)	
Personal care assistance	1.	24 (42.1)	33 (57.9)	57 (100)	<0.021
	2.	37 (57.8)	27 (42.2)	64 (100)	
	3.	24 (34.3)	46 (65.7)	70 (100)	
Adaptive equipment for health and safety	1.	23 (35.4)	42 (64.6)	65 (100)	<0.038
	2.	34 (57.6)	25 (42.4)	59 (100)	
	3.	27 (41.5)	38 (58.5)	65 (100)	

Differences Between Age Group—Statistical Significance of Future Needs

When looking at future needs, several categories had significant differences, which are highlighted in Appendix D, Table 23. This includes issues that were mentioned in previous tables. For example, about 19% of those who considered working in the community as not

important in the next 5 years were individuals aged 45-64 years old. Generally, people who were between 25 and 34 years of age were more interested in work than any other age group. They were the most likely to consider “Working in the community” important with needs met and important with unmet needs. Additionally, they expressed interest in “*Working in a sheltered workshop.*” A subset of this group was more likely than any other age group to indicate that working in a sheltered workshop was not important; however, another subset between 25 and 34 years old was significantly more likely to say working in a sheltered workshop was important and they needed more information. Furthermore, those who were between the ages of 25-34 were significantly more likely to indicate that “Financial management (e.g., budgeting)” was important. One interesting result is that people between the ages of 25-34, 35-44, and 45 -64 were all equally likely to say that “Living independently without supports” was not important.

Differences among Disability Groups—Statistical Significance of Future Needs

When looking at future needs from the perspective of disability groups, only 2 categories were significantly different: “*Adaptive equipment*” and “*Assistive technology.*” Of those who considered adaptive equipment *not* important, about 49% were individuals with autism; however, 45% who considered this as important with met needs, and about 38% who considered this important with unmet needs were individuals with intellectual disabilities (see Appendix D, Table 24).

Case Management & Support Coordination—Statistical Significance of Future Needs

When looking at future needs, several categories had significant differences which are highlighted in Appendix D, Table 25. This includes issues that were mentioned in previous tables. Those with case management had most of the sentiment except for the support coordination and case management category. In that category, 57% of those who considered it not important in the next five years did not have case management. In contrast, among those who viewed it as important in the next five years, about 85% of those with met needs and 72% with unmet needs had case management.

Key Points

- In terms of unmet needs, items directly point to the importance of social and employment opportunities in the community (see Figure 16).
- An important area of needed information focused on long-term planning and preparation.
- Another area of need included information about medical and wellness activities.
- There is an emphasis on the need for information about advocacy opportunities and disability-specific activities.

FAMILY NEEDS

The purpose of Section 4 of the survey was to identify the family needs that were most important to the respondents. Instructions in the survey instructed people with IDD to skip this section. Therefore, the results in this section only represent the needs of the 137 family members who completed the survey.

Figure 17 indicates that the most important need identified by family members was “Access to medical supports and services.” Tying into the need for medical supports is an interest in “Fitness/wellness activities or programs,” which was the second most important need identified by families. Continuing a theme from earlier sections, families are also interested in Medicaid-based services such as “Support coordination” and “Access to paid services.” Another item from previous sections includes a need for “Access to resources in my community.”

Figure 17. Most Important Family Needs

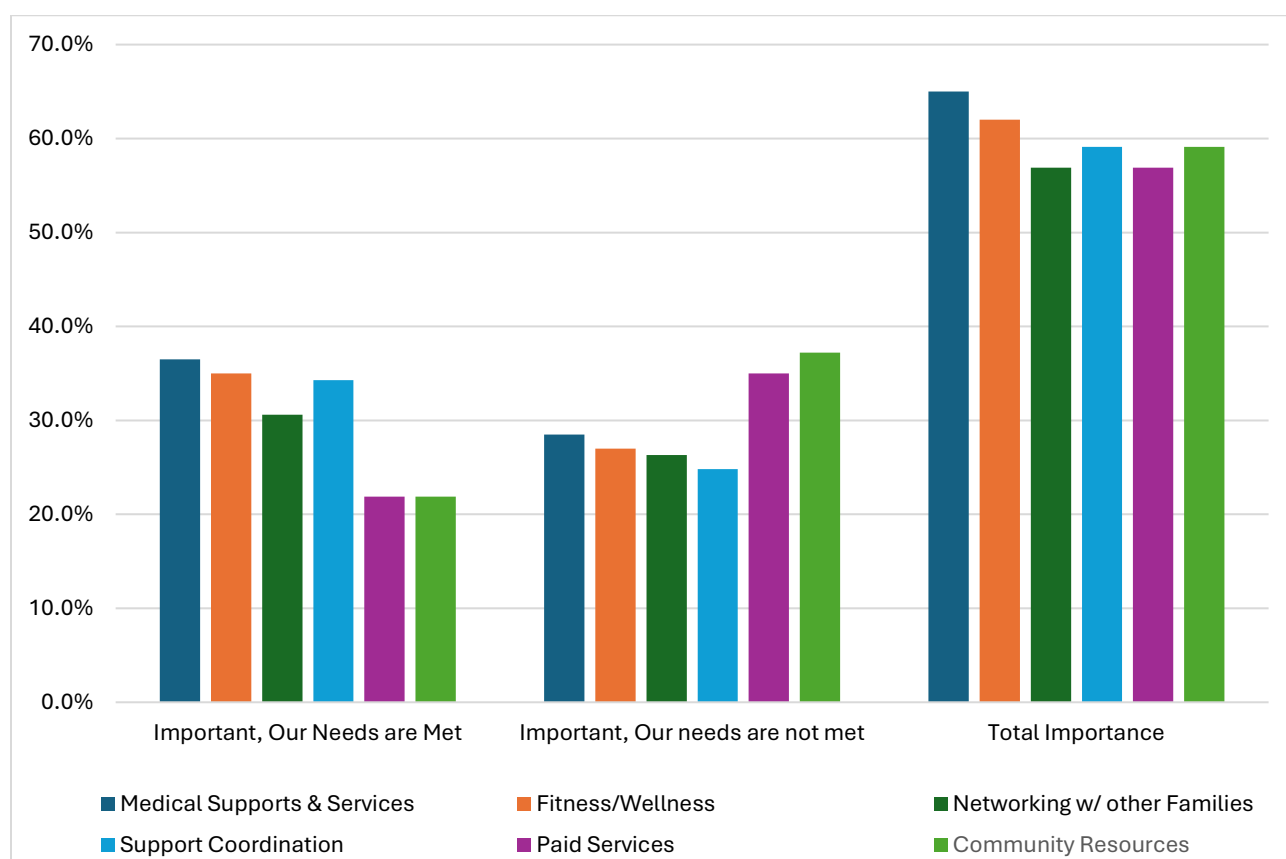
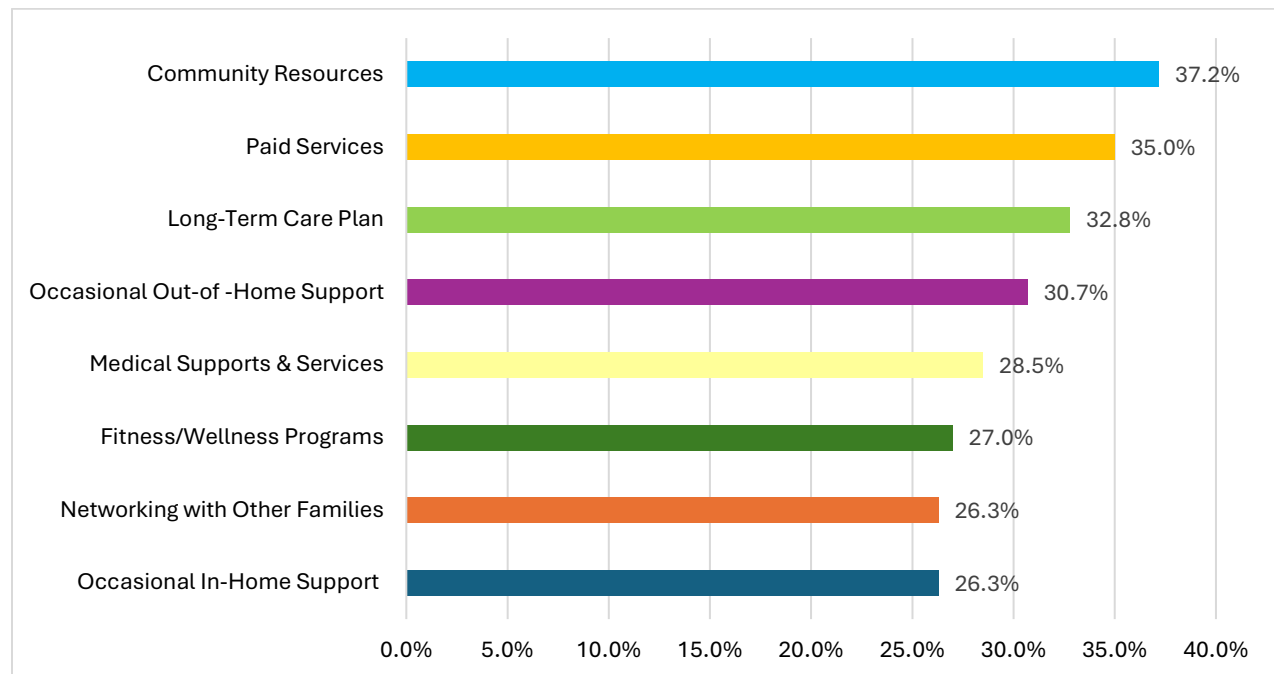


Figure 18 depicts the most important unmet needs identified by family members. “Access to resources in my community” was the most often cited unmet need. In addition to community resources, family members indicated an unmet need for “Access to networking

with other families.” Additionally, respite care in the form of “Occasional out-of-home support” and “Occasional in-home support” was also an important unmet need.

Figure 18. Most Important Unmet Family Needs



Challenges to Obtaining Supports and Services that the Family Need

One-third of family members indicated that they did not know what supports and services were available to them (see Table 15). They also said that the services they needed were not available and that the locations of service providers were challenges. Interestingly,

Table 15. Challenges to Getting the Supports and Services that You and Your Family Need		
Responses	N	Percent of Families
Does not apply	13	9.4
Not knowing what I need	20	14.6
Not knowing what is available	46	33.6
Service I need is not available	34	24.8
Service is available, but level of support is insufficient	27	19.7
Location of service providers	32	23.3
Cost of service	31	22.6
Not knowing who to ask about resources	30	21.9
Quality of services (reliability, consistency)	30	21.9
Transportation	21	15.3
Other	5	3.7
Total	289	210.8

“Transportation” was not cited as one of the most impactful challenges for families in the same way it is for individuals with IDD. Cost of services, which is not typically selected as a challenge in the earlier sections, was cited as a challenge by family members. All of these challenges align with the most important unmet family needs identified above in Figure 16.

Age Group Differences—Statistical Significance of Family Needs

When looking at family needs, the following showed significant differences: occasional out-of-home support (respite), personal care assistance, parenting skills training, and before or after school care. Like previous needs, age influenced individuals’ priorities. About 35% of individuals who considered occasional out-of-home support or respite as not important were 25-34 years old. In contrast, about 47% who considered this important with their needs met, and about 36% who considered this important with unmet needs, had family members with IDD 5–17 years old. Table 26 in Appendix E further highlights the significant age group differences.

Case Management / Support Coordination Differences—Statistical Significance of Family Needs

Table 27 in Appendix E highlights the differences between those families who received case management and those who did not. The following areas had significant differences: “Support coordination/case management services,” “Access to paid services,” “Occasional in-home support (respite),” “Personal care assistance,” and “Adaptive equipment for health and safety.” In most categories, individuals with case management made up the majority, except for the question about “Support coordination and case management services.” In that category, 71% of those who considered it not important did not have case management. In contrast, among those who viewed it as important, about 96% of those with met needs and 68% with unmet needs had case management. This may reflect the idea that those who never had it to begin with would not prioritize this category compared to those who already have it would want to continue having the service.

Key Points

- “Access to resources in my community” was the most often cited unmet need.
- Family members indicated an unmet need for “Access to networking with other families.”
- Respite care in the form of “Occasional out-of-home support” and “Occasional in-home support” was also an important unmet need.
- The greatest challenge to getting the supports and services for families was not knowing what was available.

Appendix A

Chi-Square Analysis of Daily Activities

- **Table 16: Chi Square Analysis of Daily Activities by Age Group**
- **Table 17: Chi Square Analysis of Daily Activities by Disability Type**
- **Table 18: Chi Square Analysis of Daily Activities by Case Management/Service Coordination**

Table 16: Chi Square Analysis of Daily Activities by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Working in the community	1	7 (9.0)	22 (28.2)	6 (7.7)	15 (19.2)	12 (15.4)	14 (17.9)	2 (2.6)	78 (100)	<0.001
	2	1 (1.1)	9 (9.7)	9 (9.7)	31 (33.3)	18 (19.4)	20 (21.5)	5 (5.4)	93 (100)	
	3	2 (2.7)	10 (13.3)	17 (22.7)	24 (32.0)	10 (13.3)	11 (14.7)	1 (1.3)	75 (100)	
Working in a summer employment	1	9 (6.0)	26 (17.3)	16 (10.7)	35 (23.3)	28 (18.7)	30 (20.0)	6 (4.0)	150 (100)	<0.031
	2	0 (0.0)	6 (14.6)	3 (7.3)	17 (41.5)	5 (12.2)	9 (22.0)	1 (2.4)	41 (100)	
	3	1 (2.2)	8 (17.8)	12 (26.7)	15 (33.3)	6 (13.3)	3 (6.7)	0 (0.0)	45 (100)	
Volunteering in the community	1	7 (10.0)	17 (24.3)	8 (11.4)	15 (21.4)	14 (20.0)	6 (8.6)	3 (4.3)	70 (100)	<0.001
	2	3 (2.8)	11 (10.1)	10 (9.2)	37 (33.9)	17 (15.6)	28 (25.7)	3 (2.8)	109 (100)	
	3	0 (0.0)	11 (19.3)	13 (22.8)	17 (29.8)	7 (12.3)	9 (15.8)	0 (0.0)	57 (100)	
Leisure/hobby activities	1	3 (12.5)	2 (8.3)	1 (4.2)	9 (37.5)	4 (16.7)	5 (20.8)	0 (0.0)	24 (100)	<0.034
	2	4 (3.1)	20 (15.7)	11 (8.7)	36 (28.3)	24 (18.9)	27 (21.3)	5 (3.9)	127 (100)	
	3	3 (3.4)	22 (24.7)	18 (20.2)	23 (25.8)	11 (12.4)	11 (12.4)	1 (1.1)	89 (100)	
Membership in organizations or clubs (like 4H, Scouts, Lions)	1	4 (3.8)	9 (8.6)	15 (14.3)	34 (32.4)	22 (21.0)	16 (15.2)	5 (4.8)	105 (100)	<0.010

Table 16: Chi Square Analysis of Daily Activities by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
	2	5 (6.8)	12 (16.2)	5 (6.8)	22 (29.7)	11 (14.9)	16 (21.6)	3 (4.1)	74 (100)	
	3	1 (1.5)	20 (30.3)	12 (18.2)	14 (21.2)	7 (10.6)	12 (18.2)	0 (0.0)	66 (100)	
Disability specific activities (e.g., People First)	1	1 (2.1)	7 (14.6)	6 (12.5)	16 (33.3)	10 (20.8)	8 (16.7)	0 (0.0)	48 (100)	
	2	3 (2.9)	11 (10.6)	9 (8.7)	37 (35.6)	17 (16.3)	22 (21.2)	5 (4.8)	104 (100)	<0.010
	3	6 (6.6)	26 (28.6)	16 (17.6)	15 (16.5)	13 (14.3)	12 (13.2)	3 (3.3)	91 (100)	

Table 17: Chi Square Analysis of Daily Activities by Disability Type

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Intellectual Disability	Autism	Seizure Disorder	Other	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	
Achieving personal goals	1	15 (65.2)	6 (26.1)	2 (8.7)	0 (0.0)	23 (100)	<0.038
	2	68 (40.5)	52 (31.0)	23 (13.7)	25 (14.9)	168 (100)	
	3	35 (31.2)	48 (42.9)	12 (10.7)	17 (15.2)	112 (100)	

Table 18: Chi Square Analysis of Daily Activities by Case Management / Service Coordination

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Receives CM/SC	Does not Receive CM/SC	Total	p-value
		n (%)	n (%)	n (%)	
Achieving personal goals	1	15 (65.2)	6 (26.1)	23 (100)	<0.038
	2	68 (40.5)	52 (31.0)	168 (100)	
	3	35 (31.2)	48 (42.9)	112 (100)	
Social activities in your community	1	19 (65.5)	10 (34.5)	29 (100)	<0.044
	2	91 (83.5)	18 (16.5)	109 (100)	
	3	70 (71.4)	28 (28.6)	98 (100)	
Self-advocacy	1	25 (80.6)	6 (19.4)	31 (100)	<0.037
	2	99 (81.1)	23 (18.9)	122 (100)	
	3	52 (65.8)	27 (34.2)	79 (100)	

Appendix B

Chi-Square Analysis of Life Transitions

- **Table 19: Chi Square Analysis of Life Transitions by Age Group**
- **Table 20: Chi Square Analysis of Life Transitions by Case Management / Service Coordination**

Table 19: Chi Square Analysis of Life Transitions by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 - 24	25 - 34	35 - 44	45 - 64	65 - 84	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Planning for transition into early childhood education (K-12)	1	0 (0.0)	19 (11.8)	25 (15.5)	53 (32.9)	28 (17.4)	31 (19.3)	5 (3.1)	161 (100)	<0.001
	2	7 (15.6)	15 (33.3)	3 (6.7)	7 (15.6)	6 (13.3)	7 (15.6)	0 (0.0)	45 (100)	
	3	3 (15.8)	8 (42.1)	2 (10.5)	3 (15.8)	3 (15.8)	0 (0.0)	0 (0.0)	19 (100)	
Planning for transition for school to work/adult life	1	9 (7.0)	16 (12.5)	14 (10.9)	34 (26.6)	24 (18.8)	26 (20.3)	5 (3.9)	128 (100)	<0.001
	2	1 (2.1)	9 (19.1)	2 (4.3)	15 (31.9)	9 (19.1)	11 (23.4)	0 (0.0)	47 (100)	
	3	0 (0.0)	17 (34.7)	13 (26.5)	13 (26.5)	4 (8.2)	2 (4.1)	0 (0.0)	49 (100)	
Pre-employment training	1	10 (8.6)	20 (17.2)	9 (7.8)	27 (23.3)	21 (18.1)	24 (20.7)	5 (4.3)	116 (100)	<0.001
	2	0 (0.0)	5 (10.9)	6 (13.0)	19 (41.3)	9 (19.6)	7 (15.2)	0 (0.0)	46 (100)	
	3	0 (0.0)	16 (27.6)	14 (24.1)	14 (24.1)	8 (13.8)	6 (10.3)	0 (0.0)	58 (100)	
Adult education (GED/continuing education/college education)	1	10 (7.2)	27 (19.4)	18 (12.9)	29 (20.9)	22 (15.8)	28 (20.1)	5 (3.6)	139 (100)	<0.027
	2	0 (0.0)	4 (9.8)	5 (12.2)	15 (36.6)	8 (19.5)	8 (19.5)	1 (2.4)	41 (100)	

Table 19: Chi Square Analysis of Life Transitions by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 - 24	25 - 34	35 - 44	45 - 64	65 - 84	Total	p-value
	3	0 (0.0)	8 (17.8)	7 (15.6)	20 (44.4)	8 (17.8)	2 (4.4)	0 (0.0)	45 (100)	
Services/supports planning (e.g. Medicaid, Medicare, etc.)	1	2 (4.9)	2 (4.9)	6 (14.6)	16 (39.0)	7 (17.1)	6 (14.6)	2 (4.9)	41 (100)	<0.002
	2	2 (1.9)	17 (16.0)	7 (6.6)	30 (28.3)	23 (21.7)	24 (22.6)	3 (2.8)	106 (100)	
	3	6 (7.2)	24 (28.9)	16 (19.3)	19 (22.9)	10 (12.0)	7 (8.4)	1 (1.2)	83 (100)	
Manage my budget	1	5 (7.9)	13 (20.6)	7 (11.1)	14 (22.2)	13 (20.6)	10 (15.9)	1 (1.6)	63 (100)	<0.050
	2	4 (3.8)	18 (17.1)	9 (8.6)	29 (27.6)	16 (15.2)	25 (23.8)	4 (3.8)	105 (100)	
	3	1 (1.6)	10 (16.1)	13 (21.0)	23 (37.1)	11 (17.7)	3 (4.8)	1 (1.6)	62 (100)	
Independent living skills training (grocery shopping, cooking, home management)	1	7 (13.0)	15 (27.8)	3 (5.6)	10 (18.5)	8 (14.8)	9 (16.7)	2 (3.7)	54 (100)	<0.003
	2	2 (2.0)	11 (10.8)	13 (12.7)	31 (30.4)	22 (21.6)	20 (19.6)	3 (2.9)	102 (100)	
	3	1 (1.3)	16 (20.8)	13 (16.9)	27 (35.1)	10 (13.0)	9 (11.7)	1 (1.3)	77 (100)	
Alternatives to Guardianship	1	7 (6.7)	21 (20.2)	10 (9.6)	21 (20.2)	17 (16.3)	23 (22.1)	5 (4.8)	104 (100)	<0.004
	2	2 (2.4)	7 (8.5)	12 (14.6)	33 (40.2)	14 (17.1)	13 (15.9)	1 (1.2)	82 (100)	
	3	1 (2.3)	14 (31.8)	7 (15.9)	12 (27.3)	8 (18.2)	2 (4.5)	0 (0.0)	44 (100)	

Table 20: Chi Square Analysis of Life Transitions by Case Management / Service Coordination

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Receives CM/SC	Does not Receive CM/SC	Total	p-value
		n (%)	n (%)	n (%)	
Services/supports planning (e.g. Medicaid, Medicare, etc.)	1	27 (65.9)	14 (34.1)	41 (100)	<0.038
	2	91 (86.7)	14 (13.3)	105 (100)	
	3	55 (69.6)	24 (30.4)	79 (100)	
Manage my budget	1	46 (73.0)	17 (27.0)	63 (100)	<0.044
	2	88 (84.6)	16 (15.4)	104 (100)	
	3	40 (67.8)	19 (32.2)	59 (100)	
Financial planning (able accounts, SSI, SSDI)	1	36 (69.2)	16 (30.8)	52 (100)	<0.037
	2	81 (86.2)	13 (13.8)	94 (100)	
	3	59 (72.0)	23 (28.0)	82 (100)	
Alternatives to Guardianship	1	71 (70.3)	30 (29.7)	101 (100)	<0.019
	2	70 (87.5)	10 (12.5)	80 (100)	
	3	32 (72.7)	12 (27.3)	44 (100)	

Appendix C

Chi-Square Analysis of Living Arrangements

- **Table 21: Chi Square Analysis of Living Arrangements by Age Group**
- **Table 22: Chi Square Analysis of Living Arrangement by Case Management/Service Coordination**

Table 21: Chi Square Analysis of Living Arrangements by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 - 24	25 - 34	35 - 44	45 - 64	65 - 84	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Living with parents/family	1	0 (0.0)	1 (1.4)	6 (8.6)	18 (25.7)	15 (21.4)	23 (32.9)	6 (8.6)	70 (100)	<0.001
	2	0 (0.0)	34 (26.2)	20 (15.4)	37 (28.5)	14 (10.8)	16 (12.3)	0 (0.0)	130 (100)	
	3	10 (9.3)	3 (13.0)	3 (13.0)	9 (39.1)	7 (30.4)	1 (4.3)	0 (0.0)	23 (100)	
Living independently without supports	1	0 (0.0)	27 (23.9)	12 (10.6)	22 (19.5)	18 (15.9)	19 (16.8)	5 (4.4)	113 (100)	<0.001
	2	0 (0.0)	3 (6.1)	4 (8.2)	22 (44.9)	9 (18.4)	10 (20.4)	1 (2.0)	49 (100)	
	3	10 (7.8)	8 (16.0)	12 (24.0)	16 (32.0)	7 (14.0)	7 (14.0)	0 (0.0)	50 (100)	
Living in an apartment or home with paid supports	1	0 (0.0)	29 (27.1)	13 (12.1)	23 (21.5)	15 (14.0)	15 (14.0)	2 (1.9)	107 (100)	<0.001
	2	0 (0.0)	1 (1.9)	3 (5.8)	19 (36.5)	10 (19.2)	15 (28.8)	4 (7.7)	52 (100)	
	3	10 (6.6)	6 (10.0)	13 (21.7)	22 (36.7)	10 (16.7)	9 (15.0)	0 (0.0)	60 (100)	
Living in an apartment or home with unpaid supports (e.g., family/friends)	1	0 (0.0)	26 (20.3)	17 (13.3)	25 (19.5)	21 (16.4)	25 (19.5)	4 (3.1)	128 (100)	<0.003
	2	0 (0.0)	7 (14.9)	3 (6.4)	22 (46.8)	6 (12.8)	7 (14.9)	2 (4.3)	47 (100)	
	3	0 (0.0)	3 (7.3)	9 (22.0)	18 (43.9)	7 (17.1)	4 (9.8)	0 (0.0)	41 (100)	
Living in a group home/supervised residential setting	1	0 (0.0)	29 (19.1)	15 (9.9)	43 (28.3)	25 (16.4)	27 (17.8)	3 (2.0)	152 (100)	<0.001
	2	10 (9.3)	3 (9.7)	2 (6.5)	7 (22.6)	5 (16.1)	11 (35.5)	3 (9.7)	31 (100)	
	3	0 (0.0)	5 (12.2)	13 (31.7)	15 (36.6)	5 (12.2)	3 (7.3)	0 (0.0)	41 (100)	

Table 22: Chi Square Analysis of Living Arrangement by Case Management/Service Coordination

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Receives CM/SC	Does not Receive CM/SC	Total	p-value
		n (%)	n (%)	n (%)	
Living in an apartment or home with paid supports	1	73 (68.9)	33 (31.1)	106 (100)	0.007
	2	44 (89.8)	5 (10.2)	49 (100)	
	3	49 (83.1)	10 (16.9)	59 (100)	

Appendix D

Chi-Square Analysis of Future Needs

- **Table 23: Chi Square Analysis of Future Needs by Age Group**
- **Table 24: Chi Square Analysis of Future Needs by Disability Type**
- **Table 25: Chi Square Analysis of Future Needs by Case Management/Support Coordination**

Table 23: Chi Square Analysis of Future Needs by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Working in the community	1	9 (14.1)	11 (17.2)	8 (12.5)	10 (15.6)	11 (17.2)	12 (18.8)	3 (4.7)	64 (100)	<0.001
	2	1 (1.8)	7 (12.5)	4 (7.1)	20 (35.7)	8 (14.3)	13 (23.2)	3 (5.4)	56 (100)	
	3	0 (0.0)	17 (18.9)	15 (16.7)	32 (35.6)	15 (16.7)	11 (12.2)	0 (0.0)	90 (100)	
Working in a sheltered workshop	1	10 (7.6)	20 (15.3)	19 (14.5)	34 (26.0)	20 (15.3)	25 (19.1)	3 (2.3)	131 (100)	<0.019
	2	0 (0.0)	2 (6.7)	1 (3.3)	13 (43.3)	5 (16.7)	6 (20.0)	3 (10.0)	30 (100)	
	3	0 (0.0)	11 (23.9)	7 (15.2)	14 (30.4)	10 (21.7)	4 (8.7)	0 (0.0)	46 (100)	
Membership in organizations or clubs (like 4H, Schouts, Lions)	1	3 (3.8)	6 (7.5)	13 (16.2)	32 (40.0)	12 (15.0)	10 (12.5)	4 (5.0)	80 (100)	<0.044
	2	4 (6.8)	9 (15.3)	6 (10.2)	15 (25.4)	9 (15.3)	15 (25.4)	1 (1.7)	59 (100)	
	3	3 (4.5)	18 (27.3)	8 (12.1)	13 (19.7)	12 (18.2)	11 (16.7)	1 (1.5)	66 (100)	
Achieving personal goals	1	0 (0.0)	2 (10.5)	3 (15.8)	8 (42.1)	5 (26.3)	1 (5.3)	0 (0.0)	19 (100)	<0.003
	2	8 (9.6)	12 (14.5)	7 (8.4)	14 (16.9)	16 (19.3)	22 (26.5)	4 (4.8)	83 (100)	
	3	2 (2.0)	19 (18.6)	17 (16.7)	38 (37.3)	13 (12.7)	11 (10.8)	2 (2.0)	102 (100)	
Planning for transition into early childhood education (K-12)	1	1 (0.7)	13 (9.4)	24 (17.3)	43 (30.9)	26 (18.7)	27 (19.4)	5 (3.6)	139 (100)	<0.001
	2	6 (16.2)	7 (18.9)	2 (5.4)	10 (27.0)	5 (13.5)	6 (16.2)	1 (2.7)	37 (100)	
	3	3 (13.0)	11 (47.8)	1 (4.3)	5 (21.7)	2 (8.7)	1 (4.3)	0 (0.0)	23 (100)	
Planning for transition from school to work/adult life	1	9 (7.3)	11 (8.9)	16 (13.0)	35 (28.5)	22 (17.9)	25 (20.3)	5 (4.1)	123 (100)	<0.008
	2	1 (4.2)	3 (12.5)	1 (4.2)	9 (37.5)	4 (16.7)	5 (20.8)	1 (4.2)	24 (100)	
	3	0 (0.0)	16 (32.0)	10 (20.0)	14 (28.0)	7 (14.0)	3 (6.0)	0 (0.0)	50 (100)	

Table 23: Chi Square Analysis of Future Needs by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
Pre-employment training	1	10 (9.3)	12 (11.1)	13 (12.0)	30 (27.8)	15 (13.9)	23 (21.3)	5 (4.6)	108 (100)	<0.032
	2	0 (0.0)	4 (14.3)	3 (10.7)	12 (42.9)	4 (14.3)	4 (14.3)	1 (3.6)	28 (100)	
	3	0 (0.0)	14 (21.9)	11 (17.2)	17 (26.6)	15 (23.4)	7 (10.9)	0 (0.0)	64 (100)	
Adult education (GED/continuing education/college education)	1	10 (7.9)	15 (11.8)	18 (14.2)	32 (25.2)	18 (14.2)	28 (22.0)	6 (4.7)	127 (100)	<0.016
	2	0 (0.0)	3 (12.0)	3 (12.0)	11 (44.0)	5 (20.0)	3 (12.0)	0 (0.0)	25 (100)	
	3	0 (0.0)	12 (26.7)	6 (13.3)	15 (33.3)	10 (22.2)	2 (4.4)	0 (0.0)	45 (100)	
Financial management (e.g., budgeting)	1	7 (11.3)	13 (21.0)	6 (9.7)	11 (17.7)	11 (17.7)	12 (19.4)	2 (3.2)	62 (100)	<0.023
	2	2 (3.4)	6 (10.2)	7 (11.9)	18 (30.5)	9 (15.3)	14 (23.7)	3 (5.1)	59 (100)	
	3	1 (1.2)	13 (16.0)	14 (17.3)	31 (38.3)	14 (17.3)	7 (8.6)	1 (1.2)	81 (100)	
Independent living skills training (grocery shopping, cooking, home management)	1	7 (14.9)	8 (17.0)	4 (8.5)	12 (25.5)	7 (14.9)	8 (17.0)	1 (2.1)	47 (100)	<0.003
	2	2 (2.6)	5 (6.6)	13 (17.1)	18 (23.7)	16 (21.1)	18 (23.7)	4 (5.3)	76 (100)	
	3	1 (1.3)	15 (19.5)	10 (13.0)	31 (40.3)	10 (13.0)	9 (11.7)	1 (1.3)	77 (100)	
Planning for transition from work to retirement	1	10 (8.9)	16 (14.3)	20 (17.9)	28 (25.0)	19 (17.0)	18 (16.1)	1 (0.9)	112 (100)	<0.023
	2	0 (0.0)	4 (13.8)	0 (0.0)	12 (41.4)	3 (10.3)	7 (24.1)	3 (10.3)	29 (100)	
	3	0 (0.0)	8 (14.8)	7 (13.0)	18 (33.3)	10 (18.5)	9 (16.7)	2 (3.7)	54 (100)	
Retirement supports	1	10 (8.8)	17 (15.0)	23 (20.4)	29 (25.7)	20 (17.7)	13 (11.5)	1 (0.9)	113 (100)	<0.001
	2	0 (0.0)	2 (6.9)	1 (3.4)	11 (37.9)	2 (6.9)	10 (34.5)	3 (10.3)	29 (100)	
	3	0 (0.0)	8 (15.1)	3 (5.7)	19 (35.8)	9 (17.0)	12 (22.6)	2 (3.8)	53 (100)	

Table 23: Chi Square Analysis of Future Needs by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
Living with family / parents	1	2 (2.8)	5 (7.0)	6 (8.5)	13 (18.3)	17 (23.9)	22 (31.0)	6 (8.5)	71 (100)	<0.001
	2	8 (8.5)	18 (19.1)	18 (19.1)	31 (33.0)	8 (8.5)	11 (11.7)	0 (0.0)	94 (100)	
	3	0 (0.0)	9 (24.3)	2 (5.4)	15 (40.5)	9 (24.3)	2 (5.4)	0 (0.0)	37 (100)	
Living independently without supports	1	10 (10.6)	14 (14.9)	12 (12.8)	18 (19.1)	18 (19.1)	18 (19.1)	4 (4.3)	94 (100)	<0.005
	2	0 (0.0)	5 (12.8)	6 (15.4)	10 (25.6)	7 (17.9)	9 (23.1)	2 (5.1)	39 (100)	
	3	0 (0.0)	11 (16.9)	9 (13.8)	30 (46.2)	9 (13.8)	6 (9.2)	0 (0.0)	65 (100)	
Living in an apartment or home with supports	1	10 (12.7)	12 (15.2)	9 (11.4)	19 (24.1)	13 (16.5)	14 (17.7)	2 (2.5)	79 (100)	<0.002
	2	0 (0.0)	4 (10.3)	2 (5.1)	11 (28.2)	7 (17.9)	12 (30.8)	3 (7.7)	39 (100)	
	3	0 (0.0)	12 (15.0)	16 (20.0)	29 (36.2)	13 (16.2)	9 (11.2)	1 (1.2)	80 (100)	
Access to medical supports and services	1	2 (14.3)	0 (0.0)	1 (7.1)	2 (14.3)	8 (57.1)	1 (7.1)	0 (0.0)	14 (100)	<0.001
	2	7 (7.7)	11 (12.1)	14 (15.4)	19 (20.9)	13 (14.3)	23 (25.3)	4 (4.4)	91 (100)	
	3	1 (1.0)	20 (20.8)	12 (12.5)	37 (38.5)	12 (12.5)	12 (12.5)	2 (2.1)	96 (100)	
Access to paid services	1	3 (10.3)	1 (3.4)	5 (17.2)	9 (31.0)	5 (17.2)	5 (17.2)	1 (3.4)	29 (100)	<0.009
	2	3 (4.5)	5 (7.6)	7 (10.6)	15 (22.7)	13 (19.7)	20 (30.3)	3 (4.5)	66 (100)	
	3	4 (3.7)	27 (25.2)	15 (14.0)	34 (31.8)	14 (13.1)	11 (10.3)	2 (1.9)	107 (100)	
Occasional out-of-home support (respite)	1	5 (6.5)	6 (7.8)	14 (18.2)	24 (31.2)	13 (16.9)	14 (18.2)	1 (1.3)	77 (100)	<0.032
	2	2 (4.3)	4 (8.5)	4 (8.5)	15 (31.9)	8 (17.0)	11 (23.4)	3 (6.4)	47 (100)	
	3	2 (2.7)	22 (30.1)	9 (12.3)	19 (26.0)	10 (13.7)	9 (12.3)	2 (2.7)	73 (100)	
	1	5 (6.7)	7 (9.3)	12 (16.0)	20 (26.7)	14 (18.7)	15 (20.0)	2 (2.7)	75 (100)	<0.020

Table 23: Chi Square Analysis of Future Needs by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
Occasional in-home support (respite)	2	2 (4.4)	4 (8.9)	6 (13.3)	11 (24.4)	5 (11.1)	15 (33.3)	2 (4.4)	45 (100)	
	3	2 (2.5)	21 (26.6)	9 (11.4)	26 (32.9)	13 (16.5)	6 (7.6)	2 (2.5)	79 (100)	
Personal care assistance	1	7 (12.1)	8 (13.8)	13 (22.4)	16 (27.6)	7 (12.1)	5 (8.6)	2 (3.4)	58 (100)	
	2	2 (2.9)	6 (8.6)	8 (11.4)	17 (24.3)	15 (21.4)	20 (28.6)	2 (2.9)	70 (100)	<0.003
	3	1 (1.4)	17 (24.3)	6 (8.6)	24 (34.3)	10 (14.3)	10 (14.3)	2 (2.9)	70 (100)	
Parenting skills training	1	2 (2.0)	10 (9.8)	16 (15.7)	28 (27.5)	18 (17.6)	23 (22.5)	5 (4.9)	102 (100)	
	2	5 (10.9)	9 (19.6)	8 (17.4)	11 (23.9)	6 (13.0)	6 (13.0)	1 (2.2)	46 (100)	<0.009
	3	3 (6.7)	11 (24.4)	2 (4.4)	19 (42.2)	8 (17.8)	2 (4.4)	0 (0.0)	45 (100)	
Before or after school care	1	4 (3.1)	13 (10.2)	22 (17.3)	37 (29.1)	21 (16.5)	25 (19.7)	5 (3.9)	127 (100)	
	2	3 (9.1)	5 (15.2)	2 (6.1)	9 (27.3)	6 (18.2)	7 (21.2)	1 (3.0)	33 (100)	<0.012
	3	3 (8.1)	14 (37.8)	3 (8.1)	11 (29.7)	4 (10.8)	2 (5.4)	0 (0.0)	37 (100)	

Table 24: Chi Square Analysis of Future Needs by Disability Type

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Intellectual Disability	Autism	Seizure Disorder	Other	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	
Adaptive equipment for health and safety	1	23 (32.4)	35 (49.3)	5 (7.0)	8 (11.3)	71 (100)	<0.024
	2	39 (45.3)	26 (30.2)	11 (12.8)	10 (11.6)	86 (100)	
	3	36 (37.5)	25 (26.0)	16 (16.7)	19 (19.8)	96 (100)	
Assistive technology	1	30 (39.5)	35 (46.1)	2 (2.6)	9 (11.8)	76 (100)	<0.023
	2	34 (39.5)	26 (30.2)	12 (14.0)	14 (16.3)	86 (100)	
	3	31 (35.6)	25 (28.7)	17 (19.5)	14 (16.1)	87 (100)	

Table 25: Chi Square Analysis of Living Arrangement by Case Management/Service Coordination

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Receives CM/SC	Does not Receive CM/SC	Total	p- value
		n (%)	n (%)	n (%)	
Working in the community	1	73 (68.9)	33 (31.1)	106 (100)	<0.032
	2	44 (89.8)	5 (10.2)	49 (100)	
	3	49 (83.1)	10 (16.9)	59 (100)	
Living in a group home/supervised residential setting	1	56 (87.5)	8 (12.5)	64 (100)	<0.010
	2	38 (73.1)	14 (26.9)	52 (100)	
	3	62 (69.7)	27 (30.3)	89 (100)	
Support coordination/case management services	1	6 (42.9)	8 (57.1)	14 (100)	<0.001
	2	82 (85.4)	14 (14.6)	96 (100)	
	3	61 (71.8)	24 (28.2)	85 (100)	
Occasional out-of-home support (respite)	1	49 (66.2)	25 (33.8)	74 (100)	<0.040
	2	39 (81.2)	9 (18.8)	48 (100)	
	3	58 (82.9)	12 (17.1)	70 (100)	
Occasional in-home support (respite)	1	47 (64.4)	26 (35.6)	73 (100)	<0.008
	2	33 (76.7)	10 (23.3)	43 (100)	
	3	67 (85.9)	11 (14.1)	78 (100)	
Personal care assistance	1	36 (62.1)	22 (37.9)	58 (100)	<0.003
	2	58 (86.6)	9 (13.4)	67 (100)	
	3	55 (80.9)	13 (19.1)	68 (100)	
Adaptive equipment for health and safety	1	42 (64.6)	23 (35.4)	65 (100)	<0.013
	2	48 (81.4)	11 (18.6)	59 (100)	
	3	57 (85.1)	10 (14.9)	67 (100)	

Appendix E

Chi-Square Analysis of Family Needs

- **Table 26: Chi Square Analysis of Family Needs by Age Group**
- **Table 27: Chi Square Analysis of Family Needs by Case Management/Support Coordination**

Table 26: Chi Square Analysis of Family Needs by Age Group

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Under 5	5 – 17	18 – 24	25 – 34	35 – 44	45 – 64	65 – 84	Total	p-value
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	
Occasional out-of-home support (respite)	1	3 (8.8)	3 (8.8)	12 (35.3)	9 (26.5)	1 (2.9)	6 (17.6)	0 (0.0)	34 (100)	<0.044
	2	1 (5.3)	9 (47.4)	1 (5.3)	4 (21.1)	2 (10.5)	1 (5.3)	1 (5.3)	19 (100)	
	3	1 (2.4)	15 (35.7)	7 (16.7)	10 (23.8)	5 (11.9)	3 (7.1)	1 (2.4)	42 (100)	
Personal care assistance	1	4 (12.5)	6 (18.8)	12 (37.5)	7 (21.9)	1 (3.1)	2 (6.2)	0 (0.0)	32 (100)	<0.040
	2	1 (3.3)	8 (26.7)	3 (10.0)	7 (23.3)	4 (13.3)	5 (16.7)	2 (6.7)	30 (100)	
	3	0 (0.0)	12 (41.4)	5 (17.2)	8 (27.6)	2 (6.9)	2 (6.9)	0 (0.0)	29 (100)	
Parenting skills training	1	2 (3.5)	6 (10.5)	16 (28.1)	17 (29.8)	6 (10.5)	8 (14.0)	2 (3.5)	57 (100)	<0.002
	2	2 (10.5)	10 (52.6)	3 (15.8)	3 (15.8)	1 (5.3)	0 (0.0)	0 (0.0)	19 (100)	
	3	1 (6.7)	10 (66.7)	1 (6.7)	3 (20.0)	0 (0.0)	0 (0.0)	0 (0.0)	15 (100)	
Before or after school care	1	2 (2.9)	12 (17.6)	17 (25.0)	21 (30.9)	6 (8.8)	8 (11.8)	2 (2.9)	68 (100)	<0.003
	2	2 (22.2)	6 (66.7)	0 (0.0)	1 (11.1)	0 (0.0)	0 (0.0)	0 (0.0)	9 (100)	
	3	1 (7.1)	9 (64.3)	3 (21.4)	1 (7.1)	0 (0.0)	0 (0.0)	0 (0.0)	14 (100)	

Table 27: Chi Square Analysis of Family Needs by Case Management / Support Coordination

Key:

- 1 = Not important: I do not want or need
- 2 = Important: my needs are met
- 3 = Important: but my needs are not met

*Highlighted cells show the highest row percentage

		Receives CM/SC	Does not Receive CM/SC	Total	p- value
		n (%)	n (%)	n (%)	
Support coordination/case management services	1	4 (28.6)	10 (71.4)	14 (100)	<0.001
	2	44 (95.7)	2 (4.3)	46 (100)	
	3	23 (67.6)	11 (32.4)	34 (100)	
Access to paid services	1	9 (56.2)	7 (43.8)	16 (100)	<0.033
	2	27 (90.0)	3 (10.0)	30 (100)	
	3	34 (72.3)	13 (27.7)	47 (100)	
Occasional in-home support (respite)	1	20 (58.8)	14 (41.2)	34 (100)	<0.022
	2	19 (86.4)	3 (13.6)	22 (100)	
	3	30 (83.3)	6 (16.7)	36 (100)	
Personal care assistance	1	19 (59.4)	13 (40.6)	32 (100)	<0.022
	2	25 (86.2)	4 (13.8)	29 (100)	
	3	24 (82.8)	5 (17.2)	29 (100)	
Adaptive equipment for health and safety	1	22 (57.9)	16 (42.1)	38 (100)	<0.028
	2	22 (91.7)	2 (8.3)	24 (100)	
	3	24 (88.9)	3 (11.1)	27 (100)	

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